TITLE V OF THE INDIAN HEALTH CARE IMPROVEMENT ACT 36 YEARS LATER: AN INTERPRETIVE POLICY ANALYSIS

by

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A dissertation submitted to the faculty of
The University of Utah
in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

College of Social Work

The University of Utah

August 2013

The University of Utah Graduate School

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ABSTRACT

In 1976, the United States Congress passed The Indian Health Care Improvement Act (IHCIA), which establishes the federal obligation to maintain, improve, and assure, the highest possible health status for American Indians and Alaska Natives. Title V of the IHCIA seeks to make health services more accessible to urban American Indians through federal support of Urban Indian Health Organizations. The Patient Protection and Affordable Care Act was passed in March 2010; as part of this act, the IHCIA was given permanent authorization. Today, urban Indians continue to experience significant health disparities compared with the general population, and chronic diseases are on the rise, creating more challenges for the people and the health care delivery system. There is a lack of research on the outcomes of Title V.

Traditional policy analysis looks to assess whether a policy is working. Utilizing Interpretive Policy Analysis, this dissertation identifies the different communities of meaning about Title V. According to Yanow, different communities of meaning provide alternative views in which there is no single correct formulation of a policy statement. Through interviews, extensive document analysis, and observation, this dissertation fills a void in the research literature on Urban Indian Health. In this era of health care reform, it is imperative to focus attention on a long-lasting urban Indian health crisis. Identifying the cultural understanding of this population's health inequalities may lead to socially just policy.

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CHAPTER 1

PURPOSE OF STUDY

My understanding of Indian health policy began when U.S. President George W. Bush announced his fiscal year (FY) 2007 budget on February 6, 2006. On that day, Bush proposed elimination of a slew of discretionary line items, most from health, science, and human service programs (Kaiser Health News, 2006). The Urban Indian Health Program (UIHP), the discretionary funding line item within the Indian Health Service (IHS) budget, was eliminated. Department of Health and Human Services (DHHS) officials, in justification of the President's proposed budget, said beneficiaries under UIHP were covered by other federally funded health and human services; cutting urban programs amounted to a $33 million savings and the end of what the Bush administration viewed as funding of duplicative services and unconstitutional practice of funding programs based purely on racial classification.

As executive director of an urban Indian health center during that time, 80% of our center's operating funds (totaling $1.5 million dollars) were based on federal contract and grant awards tied to the UIHP line. The client base at our health center can best be described as American Indian adults and families, who actively sought health care, were uninsured, and were living at or below the federal poverty guidelines. Conversations and e-mails among Indian Health Service officials and Urban Indian Health Programs speculated cuts to the budget in the days preceding the February 6 release, but never did

we suspect complete elimination of the program funding. The IHS budget has historically been under-funded (U.S. Commission on Civil Rights, 2003) and unadjusted for inflation or cost of living increases. The joke was that we were the best kept secret in the federal government because Indian health programs, both reservation and urban, served so many with so little. With the potential elimination of UIHP funding, what would the cost be to the provision of health care as defined by the Indian Health Care Improvement Act?

The Indian Health Care Improvement Act (IHCIA) of 1976 was created to maintain, improve, and assure the highest possible health status for American Indians and Alaska Natives, and to provide all resources necessary to effect the policy. Title V of the IHCIA authorizes assistance to urban American Indian nonprofit health organizations. Its purpose was to make health services more accessible to urban Indians by entering into contracts with these organizations for the provision of health care and referral services for urban Indians residing in areas in which such organizations are situated [§ 501, 25 U.S.C. 1651].

Background reports on urban Indian health from Minneapolis, Minnesota, and Seattle, Washington, two key federal relocation sites for American Indians established during the period of federal Indian policies known as Termination between 1945-1961 (Getches, Wilkinson, & Williams, 1993), were used by the Senate and House to support Title V, stating significant numbers of urban Indians experienced a lower standard of health than that of the general population (S. Rep. No. 94-133, 1975; H.R. Rep. No. 94-1026 Part I, 1976). As the official federal policy, the goal of Termination was for complete integration of American Indians through the dismantling of federal-tribal

relationships, imposing state legislative and judicial control, and renouncing all federal programs to tribes and individuals, in exchange for a monetary compensation to those Indians who gave up their tribal status or tribal lands (Getches et al., 1993). Once they had been "terminated" from their federal dependency and status as a tribal member, American Indians sought basic needs for themselves and their families in the cities--they relocated to urban areas.

Over time, urban Indians in Minneapolis and Seattle were experiencing higher infant mortality rates, greater frequency of alcoholism, higher levels of poverty, and increased physical and cultural barriers to accessing any type of health care (Bergman, Grossman, Erdrich, Todd, & Forquera, 1999; S. Rep. No. 94-133, 1975; H.R. Rep. No. 94-1026 Part I, 1976). In the Committee on Interior and Insular Affairs report to accompany the Senate's proposed IHCIA legislation (S. Rep. No. 94-133, 1975), it acknowledged the federal commitment necessary to address the failing health conditions of urban Indians through provisions of Title V. The report stated:

> The American Indian has demonstrated all too clearly, despite his recent move to urban centers that he is not content to be absorbed in the mainstream of society and become another urban poverty statistic. …It is, in part, because of the failure of former Federal Indian policies and programs on the reservations that thousands of Indians have sought a better way of life in the cities. Unfortunately, the same policies and programs which failed to provide the Indian with an improved life style on the reservation have also failed to provide him with the vital skills necessary to succeed in the cities. His difficulty in attaining sound physical and mental health in the urban environment is a grim reminder of this failure. (p.138)

Acknowledgement was made regarding the history of federal policy that contributed to the health problems of urban Indians as well as to the limitation of funds for urban Indian health care so that the passage of the IHCIA was intended to fulfill the federal obligation.

In *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Institute of Medicine, 2002), the Institute of Medicine (IOM) defined disparity to be any difference not due to health status or preferences for health care services, and that those differences are considered disparities if the differences are due to the operation of health care systems, the legal climate, discrimination, and other socioeconomic factors; in other words, the social determinants of health. The report went on to highlight that greater difference in quality of health exists for racial/ethnic minorities in the United States.

Urban Indian health inequalities exist today as they did 36 years ago at the time of the passage of the IHCIA, and urban Indians still experience greater health disparity rates than the majority population (Indian Health Services, 2009). Common health disparities for the urban Indian population are diabetes, depression, cardiovascular disease, HIV, and obesity (Urban Indian Health Institute, 2008). Differences in health status between the majority population and American Indian population relate to the social, economic, and historic factors that differentiate the groups; and even with the creation of a health policy for American Indians, the policy only offers support to the Indian communities to address the provision of health care access.

The Indian Health Care Improvement Act was permanently authorized in the March 2010 passage of the Patient Protection and Affordable Care Act, P.L. 111-148 (ACA). I created a table of the federal policies that led to the construction of the Indian Health Care Improvement Act, P.L. 94-437 in Chapter 2 of this dissertation. With the permanency of Title V under this Act, UIHOs enter a new political arena at the federal level for budget and policy consultation on behalf of the urban Indian populations served and for the population that has not accessed care, thereby raising the issue of

accountability and awareness of federal funding to accomplish the intent of Title V. Whereas urban Indians do not enjoy self-determination as the reservation-based tribal governments do (The Harvard Project on American Indian Development, 2008), with permanent authorization of the IHCIA, urban Indian centers may now build community capacity through political and economic power. A question now is have healthier urban Indian communities been created under Title V? It is unclear which provisions benefit service delivery--the policy, any funding associated with the policy, or the administrators within the UIHP system. Although there are numerous social determinants contributing to the health status of urban Indian communities that no one policy will ever address, passage of IHCIA may bring the policy language (and any potential funding) into the 21st century. However, those actions can only take place with the inclusion of the urban Indian health care community's meaning of Title V. For this reason, I believe it was critical to ask Title V stakeholders how they understand and use Title V rather than what the policy states as its historical intent.

As a social worker, I understand that policy is often developed in response to social problems and that the policy can dictate how the work gets done to address those social problems. I believe social problems experienced by historically marginalized populations like American Indians are the result of the U.S. historical values and ideologies, economic and political structures, and institutionalized discrimination. This dissertation addresses the perspectives of Title V and how the intent of the policy has manifested over the past 36 years in the administrative levels of the Urban Indian Health Program system.

For the purposes of my inquiry, I focused the study on urban American Indians, and use terminology interchangeably when writing about Native communities that are referred to as urban, urban Indian, or off-reservation areas. The terms American Indian, tribal, indigenous, or Indian are used to identify the collective populations indigenous to the lower 48 United States. I am not focusing my study on Alaska Natives nor Native Hawaiians, and unless otherwise noted, am not referring to their populations specific to geographic location or historic federal government relationships. I acknowledge federal Indian policies and the U.S. Census Bureau use the terms American Indian and Alaska Native (AI/AN), but within urban Indian communities, created generally by the federal relocation policies, the terms used by participants for self-identification or reference will be noted. I also acknowledge that many urban Indians are not recognized as members of a tribe due to many social, historic, and political factors, including tribal Nation determination for enrollment (i.e., blood quantum or lineage), federal policies that removed tribal Nation status, relocation of families and individuals to urban areas that cut them off from tribal resources, or identification as individual tribal members. For some Indian people born to parents from different tribes, they are ineligible for tribal enrollment because the child's blood line is not sufficient for enrollment in either parent's tribe.

There is a vulnerability attached to the designation of American Indian, and with that, the status of our health and the extent to which we are covered by the federal obligation, due to the underlying assimilation policies by the U.S. government, is a continuation of the federal response to the "Indian problem." For example, under the George W. Bush administration, the Department of Justice and Office of Management

and Budget pushed a constitutional argument that divided resources in the proposed FY2007 budget from federally recognized tribal governments and the enrolled tribal members who live off-reservation. Potentially, this action would forfeit federal obligation to provide health care services to the UIHO, since providing federal dollars for resources to American Indians living in urban areas would be unconstitutional if those dollars are granted based on "race" or "ethnicity." The threat of defining urban Indians as just another minority population threatens their status and recognition as tribal people and ultimately goes against the intent for self-determination. In the 21st century, how much authority does the U.S. federal government have to continue enforcement or classification of tribal identification, of one's "Indianess?" The point is that identity for American Indians is in itself a self-determining act, and the way in which Indians refer to themselves is reflective of the variety of distinctive tribal Nations and cultures that exist in the U.S. Self-definition is a matter of self-determination and social justice. The purpose of my inquiry is not to decide who is Indian and how much Indian they are, but rather to consider how federal policies have impacted urban Indian communities and their health service delivery systems.

Literature Overview

20th Century Indian Health Care

The Indian health care system has a complex history of federal support established through the unique legal relationship of the United States government with federally recognized tribal governments set forth in constitution, treaties, statutes, executive orders, and court decisions. However, it was the passage of the Snyder Act of 1921 that first established congressional authorization for Indian health care federal

appropriations. The Snyder Act authorized Congress to make appropriations for "the relief of distress and conservation of health" of American Indians and Alaska Natives (Public Law 67-85, 25 U.S.C. 13, 1921). Since the Snyder Act recognized the federal trust obligation to American Indians for their health, the IHCIA was created to maintain, improve, and assure the highest possible health status for all federally recognized American Indians and to provide all resources necessary to effect the policy. It is customary for Congress, through a reauthorization process, to look at major federal laws every 5 to 7 years to update and modernize policies that reflect the evolution of community needs and conditions (National Congress of American Indians and National Indian Health Board, 2006). Continuation of federal authority to maintain Indian health care services funding stems from the Snyder Act of 1921.

Both the IHCIA and the Snyder Act are policies of the 20th century. However, if discretionary funding is not made available to the programs to provide the services, as financial support has become subject to the willingness of Congress, then the statutes, court decisions, and policies are “hollow” (Westmoreland & Watson, 2006). The IHCIA establishes the legal obligation of the U.S. government to uphold federal agreements made through treaties; the administration of health services for all eligible American Indians is the responsibility of the IHS. There has never been a monetary value established to meet the obligation, though I must note that the UIHO line item is continuously under-funded for providing the care established by federal policy (US Commission on Civil Rights, 2003, 2004).

Today’s Indian health care delivery system is more than just IHS--it has become a collaboration of federal, state, local, and tribal health systems (Dixon & Roubideaux,

2001; Forquera, 2001; Rhoades, 2000; Roubideaux, 2004; Zuckerman, Haley, Roubideaux, & Lillie-Blanton, 2004). Access to health care for American Indians includes a mix of private and public sources not unlike those for other Americans. If, as the Bush Administration had recommended, UIHO funding was eliminated, then various levels of impact would occur across Indian Country. In 2006, 26 of 34 urban programs received only 51% of their budgets from IHS; two programs received 100% of their funding from IHS. Eradication of federal funding meant the likelihood of reduction of services, or even the closure of medical or outreach and prevention programs. We know that urban Indians are less likely to seek care from a tribal or IHS facility due to access issues (Zuckerman et al., 2004); if the UIHO programs were severely impacted, urban Indians would most likely seek care through public community health centers and emergency rooms--centers that are already subject to an overwhelming patient load, and for a largely uninsured and poor Indian population, unaffordable (Urban Indian Health Commission, 2007). Thirty years after the passage of the IHCIA, the cultural, physical, and economic barriers still existed in urban areas. As stated in the 2008 Urban Indian Health Institute report, "…there is no national, uniform policy regarding urban Indian health, and current federal executive policy aims to eliminate funding for urban Indian health within the Indian Health Service" (p. 1).

Urban Indian Health Status and Health Inequalities

Reliable health statistics on urban Indians are scarce because this demographic has been insufficiently researched and its community members are often misclassified on vital records as belonging to other races or ethnicities. What we do know about urban Indians' health is enough to warrant immediate action to collect data (Urban Indian

Health Commission, 2007; Zuckerman et al., 2004). As made clear in the first urban health study (Urban Indian Health Institute, 2004), there is no formal public health surveillance system for urban Indians. Federal, state, and local public health institutions might collect such data, but they are rarely *disaggregated or separately analyzed* for American Indian data (Urban Indian Health Commission, 2007, p. 10). Due to the overall low percentage of American Indians in the U.S. population (and lack of funding to conduct large-scale American Indian-specific research), Indian data samples are rare and often, Native peoples are combined with other minority populations for the purpose of statistical significance. Health data that specifically identify and sample from urban Indian populations could have a significant impact on the system of care for urban Indians because accurate data could inform policy and funding distribution.

Any current literature on the health status of urban Indians consistently reveals a connection between the high levels of risk factors/health issues and poverty (Urban Indian Health Institute, 2008); the recognition of poverty and health disparities was first noted in the Meriam Report. In 1928, the Institute for Government Research (later to become the Brookings Institute) issued a report, *The Problem of Indian Administration,* documenting Indian life and the problems of governmental administration of Indian affairs. Known as the Meriam report for the name of the principal investigator, this report documented a host of social, cultural, health, and economic ills, including substandard living conditions and poverty. The report highly criticized how the federal government discharged its trust responsibilities for American Indians (Snipp, 2000). The IHS administers the federal trust to provide access to health care for urban AI/AN. Unfortunately, urban Indian health organizations suffer a significant lack of funding for

direct care and health promotion/disease prevention outreach, which is believed to be an underlying factor in the growing health disparities of an urban population (U.S. Commission on Civil Rights, 2003). Health disparities identified in the research highlight the prevalence of chronic disease, the structure and use of health care services, and an American Indian marginalized socioeconomic status (US Commission on Civil Rights, 2003, 2004; Urban Indian Health Institute, 2004, 2008). Studies from the Urban Indian Health Institute have found that urban AI/AN suffer from significant health disparities compared with the general population. These disparities include higher rates of tobacco use, infant mortality, later prenatal care, interpersonal violence, attempted suicide, and deaths due to diabetes, accidents, and chronic liver disease.

Other key findings point to differences existing between urban Indians and the rest of the U.S. population in terms of access to healthcare, risk behaviors, threats to health, and certain health outcomes. For example,

1. Almost 30% of urban AI/AN report not having health insurance, compared with 18% of non-AI/AN
2. Nearly 1/3 of urban AI/AN have a body-mass index greater than 30 (obese), compared with 20% of non-AI/AN
3. 24% of AI/AN living in UIHO service areas experience poverty below 100% of the federal poverty guidelines compared to 13.5% of the general population living in the same areas
4. 30% of AI/AN under the age of 18 experience poverty below 100% of federal poverty guidelines in the same areas

(Urban Indian Health Institute, 2008)

The IHCIA was enacted into law based on the continued decline in health status of American Indians compared to the general population, and with its passage, the IHCIA affirmed that it was the policy of the U.S. government to elevate that health status of **all** Indian people to the parity of the general U.S. population. Why then has there been no clinically significant improvement of the health of urban Indians since 1976? As

Forquera suggests (Urban Indian Health Commission, 2007), a majority of urban Indians continue to think from a tribal perspective having been removed from the physical Indian experience of reservations. The challenge to maintain one's Indianess in a society that prioritizes individualism over the collective has prevented efforts to address health disparities that affect Indian people.

Threats to Federal Funding

In general, Indian health is the result of the U.S. federal trust obligation. American Indian health services provided by the federal government date well before the concepts of discretionary line item spending arose (Westmoreland & Watson, 2006). For example, provision of health care to Indian tribes was part of land treaties as early as the 1830s (The Harvard Project on American Indian Economic Development, 2009). Even though more people who are Indian live in cities than on reservations, federal policy toward Indian affairs continues to focus its information-gathering and financial resources on reservation communities (Urban Indian Health Institute, 2004). According to a report from the DHHS Office of Minority Health, as of 2008, an estimated 4.9 million people identified as American Indian or Alaska Native in combination with one or more races; of that number, 1.9 million live on federal trust lands or reservations and 60% live in urban/metropolitan areas (Office of Minority Health, 2010). In FY06, the same year President Bush proposed elimination of urban Indian health for the FY07 budget, Congress spent $32.7 million on the Urban Indian Health Program, which amounts to approximately 1% of IHS's $3 billion annual budget (The Harvard Project, 2009; Urban Indian Health Commission, 2007). In 2005, the UIHO served roughly 100,000 Indians in their centers. In the 21st Century, it is funding, more so than the IHCIA, that is essential

to the livelihood of UIHOs. However, reliance on federal dollars has produced a system that is (a) insufficient and unreliable and (b) associated with ongoing health disparities (Schneider, 2005; US Commission on Civil Rights 2003, 2004; Westmoreland & Watson, 2006). There was a joke among Indian health care providers that you never wanted to be sick and in need of care after June; assumingly, IHS funded facilities would run dry by the third quarter of a fiscal year of federal funding. At that point, funding was restricted to cases of life or limb until October 1, the beginning of the federal fiscal year. Among urban Indian centers, like all good jokes that change with the times, you never want to be sick after February because limited funding paired with increased need fiscally drained the programs by the end of the second quarter. The funding shortfalls to IHS, tribal, and urban health facilities cause a system wide rationing of services to preserve any remaining, limited funding.

It is well documented that IHS is funded at a level of only 54% of what is needed, and that the urban Indian health per capita funding levels are even greater in need (Dixon & Roubideaux, 2001; Forquera, 2001; US Commission on Civil Rights, 2003, 2004; Westmoreland & Watson, 2006). Since the creation of the Congressional Budget Act, Indian health programs have fallen under discretionary spending. What will the health of urban Indians be if Congress continues to allocate just over 1% of the federal annual appropriations for Indian health? The FY10 Interior and Environment Appropriations bill signed into law by President Obama provides IHS with a budget of $4.051 billion; the urban Indian programs will receive just over 1% of that amount in the amount of $43.1 million (Council on Social Work Education, 2009). In 2008, the U.S. spent about $7,681 per resident for health care while health care expenditures grew at a rate of 4.4%

"outpacing inflation and the growth in national income" (Kaiser Family Foundation, 2010). The urban Indian population along with the growing cost of health care continues to rise at rates far beyond the government's funding. As described in the State of Native Nations (The Harvard Project, 2008),

> Certainly, differences in health status between the U.S. general population and the American Indian and Alaska Native population relate to the significant social, economic, and history-dependent factors that differentiate the groups. Yet, the differences are also a product of a health-care system that, because of financial and managerial shortcomings, often cannot provide needed services. For two decades or more, the Indian health system has witnessed an increasing service population, rising per-patient demand for services, increasing costs of labor and goods, and stagnant budgets. (p. 222)

The Obama Administration and Healthcare Reform

In a time of economic and social seriousness, how do we set priorities for health? In the second year of the Obama Administration, there was an increasing pressure to move toward a universal health plan for the U.S.; at the same time, the U.S. also experienced its worst financial crisis since the Great Depression. An underlying contradiction with the U.S. economic system is this: it can produce great abundance and stability, and then create the negative consequences of recession and depression. Health has become a global concern since it is seen as a vital investment in economic development and poverty reduction. In January 2009, the Director-General of the World Health Organization (WHO) convened a global consultation among government and public health officials on the connection between financial turmoil and global health. This meeting was convened because WHO officials expressed a mounting concern that public health in their own countries would worsen due to economic instability, increased unemployment, erosion of savings and pension funds, failure of the safety nets for social protection, and reductions in government health spending. Along with these concerns

was the worry of an increase in mental illness and anxiety, and a possible jump in the use of tobacco, alcohol, and other harmful substances (World Health Organization, 2009). Public health is most fragile during times of crisis, and in times of economic crisis, people are less likely to seek care or are more likely to self-medicate using unhealthy substances or adopting unhealthy behaviors. A report from the Organisation for Economic Co-Operation and Development (OECD) confirms that total spending on health care in 31 countries is rising faster than economic growth, thereby placing pressure on government budgets to sustain their health care systems (OECD, 2010) while reducing budget deficits. The WHO and its commission on the Social Determinants of Health believe access to health care is a fundamental entitlement and responsibility of governments. Whether the belief is to protect a country's economic or public health, investment in health and social structures is essential to maintain stability and security, and accelerate economic recovery. The challenge facing the world now is to avoid an economic crisis becoming a social and health disaster (World Health Organization, 2009). Like the history of federal Indian health policy, managing expectations and containing escalating health care costs is critical, while under the same federal policy, these decisions are at the discretion of individual governments.

As the conversation in the 1970s was about Indian health raising the health status of ***all*** American Indians and the creation of programs to address access, today, the discussion among U.S. policymakers has switched to health care reform and health care financing (Gold, 1999). In addition, the IHCIA went without its congressional review for reauthorization from 1992 to 2009. During these 17 years, the IHCIA was ignored for reauthorization and the U.S. health care delivery system was revolutionized while the

Indian system for health care was not (Lambrew, Podesta, & Shaw, 2005; National Congress of American Indians and National Indian Health Board, 2006). IHCIA reauthorization proposals had been introduced into four Congresses during that 17 year stretch; however, none passed for various reasons of economy, interest, language of the bill, or threat of Presidential veto (New York Times editorial, 2008).

There is a renewed interest in Indian policy with the Obama presidency making efforts to address a critical lack of federal obligation for Indian treaty rights or enforcement of existing federal Indian policies. Further analysis of the federal trust obligation and the federal Indian policies of the 20th century will be discussed in Chapter 2. Acknowledgement was made by Obama during a Tribal Nations Conference held at the White House that the history between the U.S. and Tribal Nations was marked by "violence and disease and deprivation," and treaty promises were violated or broken. An article in the New York Times noted that Obama "emphasized Indian issues more than most presidents" (Belluck, 2009). Funding was established for Indian Country through the American Recovery and Reinvestment Act. Under this act, new schools were to be built on reservations (Herrmann, 2009). The signing of the Tribal Law and Order Act established accountability measures for federal agencies responsible for investigating and prosecuting reservation crime by providing tribes with additional tools to combat crime locally (Savage, 2010). Indian health care policy issues became part of the Administration's overall health care overhaul. Kathleen Sebelius, Secretary of the U.S. DHHS, publicly promised tribes that the President supported special consideration for American Indians in terms of health care reform (Miranda, 2009). Not since the creation of the IHCIA had an Administration so publicly acknowledged the overdue need to bring

improvements to the Indian health system and address the extreme health disparities that afflict Indian communities. The future of our Indian health system requires continuing evolution and adaptation to address historic and emerging health challenges beyond the lofty goals of the IHCIA policy provisions.

Failure to reauthorize the IHCIA prompted its inclusion into the Health Care Reform bills with congressional support; both the House and Senate took similar action in their bills to address the IHCIA. At the time the House was strategizing its health care reform bill, the intent was to pass authorization of the IHCIA and then come back during the next congressional year with a technical bill to correct the shortcomings of the legislation. This approach generally makes it easier to fix problems once the federal authority exists. Within the authorization, UIHP was successful in getting an additional $6.9 million for FY 2009, the largest single increase in history. Funding is part of the issue; language that strengthens urban Indian health standing in Indian Country is important as well. The U.S. Census reports over 60% of AI/AN populations live in urban settings, yet primary funding goes to tribal health systems. Since the IHS continues to budget only 1% of its annual budget to the provision of urban Indian healthcare, it is clear that the federal government lacks an understanding of the current residential status of American Indians and perpetuates an ideological view that Indians live on reservations.

Federal Indian policy overwhelmingly focuses on tribal governments and reservations rather than on American Indian individuals regardless of where they live. Another reason why we need to look at the Indian health care policies is that the delivery system of care was developed in the 1950s--prior to the federal relocation policies. Why then does funding continue to be based on a reservation delivery system? American

Indians are not living in the past or on reservations, so why are the policies? It can be argued that tribal enrolled Indians who live off-reservation still remain Indian and as such, treaty rights presumably stay with their identity and status. However, urban Indians often find themselves cut off from support systems and the health and welfare services that are provided on their tribal reservations. The relative lack of tribal services for off-reservation tribal people raises a fundamental question about the rights and treaties upon which federal assistance to Indians is implied, as well as the lack of recognition that it was federal policy that created the status of urban Indians.

With the passage of the Patient Protection and Affordable Care Act (H.R. 3590) on March 21, 2010, came the unforeseen inclusion of the permanent authorization of the IHCIA under the Indian Health Care Improvement Reauthorization and Extension Act of 2009. President Obama signed the bill (P.L. 111-148) into law March 23. In a statement released by the White House, President Obama declared,

> I signed into law the Patient Protection and Affordable Care Act, the health insurance reform bill passed by Congress ... [T]his bill permanently reauthorizes the Indian Health Care Improvement Act, which was first approved by Congress in 1976. As a Senator, I co-sponsored this Act back in 2007 because I believe it is unacceptable that Native American communities still face gaping health care disparities. Our responsibility to provide health services to American Indians and Alaska Natives derives from the nation-to-nation relationship between the federal and tribal governments. With this bill, we have taken a critical step in fulfilling that responsibility by modernizing the Indian health care system and improving access to health care for American Indians and Alaska Natives. (Office of the Press Secretary, 2010)

This passage brings Indian healthcare into the national reform conversation as well as the placement of urban Indian health organizations into the political arena. With the permanent authorization of the IHCIA, the UIHOs will be responsible for implementing key aspects of service delivery in the ACA/P.L. 111-148, including ability

to expand service delivery outside their (federally recognized) urban center. The ability to expand beyond where they have been providing services (and to whom) means UIHOs have the potential to become community health centers, thereby placing the urban Indian health delivery system into a larger community-based system of health care delivery for all Americans.

This change to the urban Indian health delivery system could have an impact on the status of urban Indians and possibly threaten their ability to continue receiving Title V funding (much like the unconstitutionality position taken by the Bush Administration in justifying the elimination of UIHP from the budget, if urban Indian programs were providing community health care, their funding as an Indian organization could disappear). Perhaps the permanent authorization of the IHCIA reinforces the federal trust responsibility to all American Indians no matter where they live. However, if Congress fails to appropriate funding to the UIHP, then the statutes, court decisions, and policy would become another "hollow" federal Indian policy (Westmoreland & Watson, 2006).

What Is Missing?

The American Indian population continues to experience significant disparities in health status compared with the general population, and now, chronic diseases are on the rise, creating more challenges for the people and the health care system (Roubideaux, 2004). The Indian health system continues to try to meet the federal trust responsibility to provide health care for American Indians despite significant shortfalls in funding, resources, and staff (Renfrew, 2006; Trombino, 2005; U.S. Commission on Civil Rights 2003, 2004; Wilkins, 1992). There is also a lack of resources to identify the impact the

32 UIHOs[1] have on the health promotion of urban Indians within their service areas; other than the Urban Indian Health Institute in Seattle, the UIHOs use their limited funding to provide services, not conduct research. Just as federal Indian policy of the 1950s was enacted as a form of assimilation, so too has there been a continued push to assimilate American Indians into a Western, colonial structure of service delivery by promoting and encouraging urban Indians to access federal programs available to (or like) all Americans; there is a push by the U.S. DHHS for UIHOs to pursue status as federally qualified health centers, thereby increasing federal funding opportunities and access to care in the urban communities. Urban Indian health programs were created to provide the federally obligated access to health care and formalized under the auspices of Title V of the IHCIA. In this time of health care reform and permanent authorization of the IHCIA, it is imperative to focus attention on the long-lasting urban Indian health crisis by identifying the contextual understanding of the population's health inequalities as they relate to Title V.

Nowhere in the literature has there been a review to understand what the policy means to Title V stakeholders, or how the policy is demonstrated in their communities to address urban Indian health disparities. Is Title V "working" as intended by policy makers, or did the policy create a structure that has grown antiquated? How was Title V interpreted and disseminated from its passage in 1976 to its 2010 permanent authorization among urban Indian health program executors?

[1] As of Fall 2011, the UIHP defunded 1 of its 34 programs: Detroit, MI. There is a nationwide needs assessment being conducted by Kaufman and Associates to determine potential/new UIHOs in 18 urban locations. There is also talk of the Detroit program re-opening.

This dissertation set out to give voice to the people who work in and for urban Indian health and their relationship to Title V, a federal policy that was created to reduce the health inequalities of urban Indians. Since the policy's inception, there has been no research with stakeholders about how Title V is understood, what it means, and how it is used to address the health disparities in urban Indian communities. My dissertation fills this gap in our knowledge of urban Indian health care systems of delivery and the impact Title V and the IHCIA have had over these past 36 years.

Research Questions

The common factor in providing urban Indian health is Title V of the IHCIA, because it establishes federal recognition and support of UIHO. The purpose of the IHCIA is to assure the health status for Indians and urban Indians by providing *all* resources necessary to affect the policy. This language differs from the original verbiage of the Act that claimed it was to raise the health status of American Indians to the *parity* of the general society. The IHCIA defines the measures of health status that Congress wishes to support for achievement; however, there is no research a) on the outcomes of Title V or b) perspective or understanding from the stakeholders about how service delivery is impacted by Title V.

Traditional policy analysis looks to assess whether a policy is "working." Utilizing Interpretive Policy Analysis (Yanow, 2000), this study identifies the different communities of meaning about Title V and how those meanings guide service delivery or administrative responsibilities in the UIHP. The term "community" refers to people who share an interpretation of a policy or implementing agency artifacts (policy), and do not necessarily share a geographic basis of the term (Yanow, 2000).

According to Yanow (2000), different communities of meaning provide alternative views in which there is no single "correct" formulation of a policy statement. Therefore, we must unlock the perspectives of stakeholders to provide the meanings that are hidden and are missing from the assumptions of policymakers. I put forward the following questions:

1. How did the federal trust obligation to provide health care to all AI/AN adapt to the growing urban Indian population?
2. Nearly 36 years after its passage, what is the interpretation of Title V by those providing health care access to urban Indians
3. How are UIHOs understood in federal health care policies?

Theoretical Frameworks

The history of American Indians is inherently linked to the relationships between the colonizer and the policies enacted to deal with what was often perceived as the "Indian problem." I contend that the health of contemporary American Indians is linked to this past and with the history of federal U.S. Indian policies that promoted assimilation or decimation of American Indian peoples. The goal of these policies were to cut Indigenous peoples from their culture that was intrinsically tied to where they were born, raised and taught their families, sought health and wellness, accessed nutritional and spiritual resources, and buried their dead, essentially leaving what was assumed by the U.S. government as no option but assimilation. These two altering forces, colonization and federal Indian policy, contributed to a cultural and social existence with, "… a lack of economic opportunity, scarcity of nutritious food, environmental degradation, stress resulting from racial stratification, historical trauma, and cultural loss, and other inequities" (Chinitz & Christian, 2009, p. 14).

These social determinants compromise the physical and mental well-being of American Indians. It does not appear that health status is determined just by the availability of health services or prescription drugs; it is the result of layers of factors such as political history, socioeconomic status, level of education, spiritual wellness, cultural and family support systems, employment opportunities, tribal status, etc. Just as American Indians have shown resilience and adaptation to maintain their ways of life, and with limited or no access to federally funded IHS facilities, urban Indians have begun to weave a network of support systems and partnerships among federal, tribal, and private foundations in order to address all these factors, which contribute to the health and well-being of urban Indians seeking health care. Although the purpose of Title V was to make health services more accessible to the urban Indian population, why have UIHOs found it necessary to create these partnerships?

Just as the Indian health care system is a complex history of federal support established with federally recognized tribal governments through constitution, treaties, statutes, executive orders, and court decisions, these policies were the result of centuries of cultural suppression, deprivation, and arguably left many tribes dependent on the federal government. As the major 20th -century policy that induced Indians to move away from their reservation homes, the federal termination and relocation programs of the 1950s changed the landscape of Indian Country. Federal policies forced a collective focus on Indian issues into a singular, government response to tribal governments or reservations, but the Relocation Acts in the 1950s impacted individual American Indians moving off-reservation by effectively cutting off cultural and social ties. Indians placed in these communities created space they could call their own, including creation of Indian

centers that provided services for health (Lobo & Peters, 2001). The irony of the body of U.S. Indian policy is that it relates primarily to tribal jurisdiction and lands, and little to individual tribal members. If the intent of 20th century policies were for assimilation and encouraged Indians to accept an American way of life, individualism, then urban Indians are truly citizens of two nations, two cultures. To understand the complex political reasons for and experiences of urban Indian life and their delivery system of care, I am using a theoretical framework that addresses these complexities from an Indigenous perspective.

Tribal Critical Race Theory

According to Denzin, Lincoln, and Smith (2008, p. 73), "…CRT (critical race theory) is not limited to the old notions of race. Rather, CRT is a new analytic rubric for considering difference and inequity using multiple methodologies--stories, voice, metaphor, analogy, critical social science, feminism, postmodernism." CRT values experiential knowledge as a way to inform thinking and research. Brayboy (2005) defines Tribal Critical Race Theory (TribalCrit) as a framework that provides a way to address the complicated and unique relationships created between American Indians and the United States federal government. While it emerges from CRT, TribalCrit also values narrative and stories as important sources of data. There are nine tenets of TribalCrit:

1. Colonization is endemic to society.
2. U.S. policies toward indigenous peoples are rooted in imperialism, White supremacy, and a desire for material gain.
3. Indigenous peoples occupy a liminal space that accounts for both the political and racialized natures of our identities.
4. Indigenous peoples have a desire to obtain and forge tribal sovereignty, tribal autonomy, self-determination, and self-identification.
5. The concepts of culture, knowledge, and power take on new meaning when examined through an indigenous lens.

6. Governmental policies and educational policies toward indigenous peoples are intimately linked around the problematic goal of assimilation.
7. Tribal philosophies, beliefs, customs, traditions, and visions for the future are central to understanding the lived realities of indigenous peoples, but they also illustrate the differences and adaptability among individuals and groups.
8. Stories are not separate from theory; they make up theory and are, therefore, real and legitimate sources of data and ways of being.
9. Theory and practice are connected in deep and explicit ways such that scholars must work towards social change. (Brayboy, pp. 429-430)

Criticisms surround the use of CRT when the research and analysis center solely on race (Darder & Torres, 2004). If race-centered, the research perpetuates the justification of a peoples' assimilation, degradation, or colonization. TribalCrit acknowledges that American Indians are more than a racial classification and, though their lived experience has a connection to colonization, their narratives must be explored to understand the connection to who they are today and move away from a romanticized, dominant, or outsider view of who Indians are. At the intersection of federal Indian policies that created the trust responsibility to provide health care and urban relocation under the guise of providing more services and opportunities, is a space that urban Indians define for themselves. Beane points out (The Harvard Project, 2008) that urban Indians do not enjoy self-determination. While reservation Indians organize decision-making processes within their tribal governments, urban Indian communities are organized around the delivery of various services like a health center (p. 363) and have no clear organizing entity created through federal policy. The liminal space (where the political and racialized identities meet) that exists in an urban Indian health community may determine how urban Indians view themselves and their way of knowing Title V; these communities of meaning may vary by geographic location, type of service agency

or tribal affiliation, and in their own ways represent how self-determination exists within urban Indian communities.

As suggested by Brayboy (2005), dominant theories do not "explicitly address issues that are salient for and to American Indians." The use of TribalCrit is significant to this research because the concern with understanding Indigenous issues is bringing value to Indigenous ways of knowing or locating theory that best fits the analysis of data without attempts to diminish the unique voice of my participants. The tenets of TribalCrit offer explanations about how urban Indians became a marginalized population and why the policies and services available to urban Indians are limited. TribalCrit, as my theoretical framework, will give meaning to the social determinants that impact service delivery and access to care in urban Indian communities, thereby helping me to build substantial knowledge regarding the urban Indian health care system in relation to the policy created explicitly for these communities. This study draws upon Brayboy's theory to link the literature to the stakeholder interviews, as well as to understand why research is lacking on urban Indian health. The definition of Title V and what meaning it has for the various stakeholders is a crucial question I addressed, so I use this framework to understand the emerging themes from interviews in relation to federal Indian history and policies.

Interpretive Policy Analysis

Interpretive policy analysis (IPA) explores the symbolic relationship and implied knowledge of a policy. The meaning of that policy comes from the values, feelings, or beliefs expressed and how those meanings are communicated to and understood by various audiences. According to Yanow (2000), different communities of meaning

provide alternative views in which there is no single "correct" formulation of a policy statement. Therefore, we must unlock the perspectives of stakeholders to provide the meanings that are hidden and missing from the assumptions of policymakers. Yanow describes the importance of identifying the symbolic artifacts, or policy artifacts, as they accommodate multiple meanings--to identify the various meanings carried by specific artifacts as interpreted by the different communities (Yanow, 2000). In urban Indian health policy, what are the implications of these different, and possibly conflicting, meanings for the implementation of Title V?

IPA as a framework is strongly connected with its research methods; IPA is a framework through which to conduct document analysis and identify stakeholders, communities of meaning, and policy artifacts. It assists in my identification of the groups of people (known as *communities*) who might share understandings of policy ideas and language that would be different from other groups' understandings, and to identify the artifacts through which these understandings are expressed, communicated, and interpreted (Yanow, 2000, p. 27). This framework is important because these understandings are most likely the driving force, whether explicit or implicit, behind actions stakeholders make in providing health care resources when they approve Title V contract or grant costs, make decisions for the level of care provided at a UIHO, or determine the types of services they can or will provide in their urban Indian health organization. From interviews conducted with stakeholders, I clarify the types of meanings given Title V, and how these professionals demonstrate their understanding of the policy through shared communities of language, definitions, or the way in which health care services are provided. The analysis of Title V and any recommendations

regarding its future are based in the interpretive analysis of the values, beliefs, and feelings that come from the conversational interviews. More important is acknowledging the opinions, the experience, and the voice of these participants. The purposeful act of silencing minority populations creates oppression and marginalization. One of the principles of social justice is hearing what has been muted or left out of the conversation; policy contributes to the survival of a society, but it can also enforce social control. In the case of policy making, giving voice to the people affected by legislation on the ground, along the front-lines of the day-to-day work, is a way for policy makers to receive feedback. Or in the case of this study, sharing the meanings of my participants connects the lived experience of Indian and non-Indian alike working in or for the delivery of urban Indian health care. Perhaps this is critical to the success of the organizations and the future of Title V. I believe giving voice to Title V stakeholders is an important first step in understanding the effects and ramifications of this policy, because until now, it has not been sought after.

Methodology

This dissertation gives voice to the UIHO population that is rarely researched for their experience, and discovers how a federal policy intended to improve access to health care for urban Indians is understood; both these components contribute to an understanding of Title V that has never been explored since the inception of the policy. This exploratory study was not intended as a traditional policy analysis that looks to measure outcomes based on the intent of the IHCIA/Title V authors in 1976. Rather, this was an exploration of those whose understanding of the policy is central to the administration of the federally funded urban Indian health care delivery system.

As a federally recognized tribal member who resides off-reservation (I am an urban Indian), I wanted to define the meaning and relationship of urban Indian health to Title V of the IHCIA. Traditional American Indians often view ill health as an imbalance among mental, spiritual, emotional, physical, and social states (Smyer & Stenvig, 2007). This study is looking at the policies that impact the population's health and how specifically Title V is comprehended. Understanding my exploratory inquiry about health through a cultural lens is an essential component to understanding the perspective of my Native participants; that same perspective is also critical for creating socially just health policies for urban Indians.

If Title V was considered the "right" action regarding health services then, what is the interpretation of the policy by those providing health care access to urban Indians now? In this descriptive-exploratory study presented in Chapter 3, I explored the meaning of Title V in urban Indian communities (the term *communities* or *community* used as a reference to people who share an interpretation of, or implementation of, a policy, not the shared geographic location of the term *community*) from the perspectives of administrators within Urban Indian Health Organizations (UIHO), Indian Health Service, or administrative stakeholders identified by document analysis and conversational interviews. Through interviews with these professionals, I ascertained the different communities of meaning about Title V and how they contribute it to health care delivery.

Through in-depth interviewing with UIHP stakeholders, in Chapters 3 and 4, I translated Title V/urban Indian health communities of meanings as valid, valued, and authentic. My life experience as an urban Indian and UIHO executive director lends to an

Indigenous approach to understand my research and my research participants. When one looks at research conducted about American Indians, one sees the terms vulnerable or disadvantaged to describe the conditions of the participants, their situations, or their pasts. These researchers often use their research as a means to promote social justice by looking at the contextual issues and history underlying the conditions of the participants and their situation to understand their past. As Linda Smith notes, the role of an Indigenous researcher is to produce research knowledge that documents social injustice and creates space for voices kept silent to be "listened to" (Denzin, Lincoln, & Smith, 2008; Smith, 2006).

Research Design

My design is informed by a constructivist ontology that values inclusiveness, pluralism, and strives to ensure my participants' voices are present in the construction of meaning (Denzin & Lincoln, 2005). As delineated by Marshall and Rossman (2006), reflection on my identity and perspective as an urban Indian and as a former UIHO executive director lends to the design of this qualitative study with consideration given to the scope of my intent, purpose for reflexive questioning, and data analysis. I interviewed stakeholders from UIHO communities and federal agencies who are linked to Title V. Any issues of reflexivity are addressed, as my role is not merely as interviewer or researcher, but that my identity is also as a member of the urban Indian community and as a former UIHO executive director. I identify and present communities of meanings so that they can be translated and used for health service delivery policy making. Specifically, this study provides a) an understanding of urban Indian health and b) a potential explanation about why health disparities remain prevalent.

This study is a collective inquiry because I am interested in the urban Indian health care communities' understanding or meanings regarding Title V; perhaps no other policy analysis of urban Indian health has occurred (in publication) because the analysis of policy focuses on good versus bad policy or the final analysis render the results as a singular voice that for the Indian stakeholders their responses and understandings represent a singular understanding. Use of tribal critical theory addresses this, as does a discourse in Indigenous knowledges. In this study, I am adding to the knowledge gap by bridging traditional, Western methodologies with a growing indigenous perspective in research.

Participants

To understand the consequences of a policy for the broad range of people it was intended, I required local knowledge of the everyday and the expert understandings of practical experience with Title V. There is a difficulty and limitation in sampling urban Indians because the population that actively seeks care or is connected to its community is never comprehensive of the total or estimated census population. For this original research, I overcame this limitation by focusing my attention on the policy-driven levels of urban Indian health care. Though no longer employed by a UIHO, I still knew how to connect with a majority of UIHO executive directors, IHS staff and administrators, and with staff of the National Council of Urban Indian Health, which is a membership-based organization serving as a resource center providing advocacy, education, training, and leadership for urban Indian health care providers. Through my continued association with urban Indian health providers, advocates, and administrators, I conducted conversational interviews with the key actors engaged with Title V. A key informant

approach allowed me to explore the meaning of Title V in-depth from individuals recognized for their central role in Title V efforts. Though interviews have their limitations, my familiarity with my participants and the work they do provided a solid base from which I built their interest for participation, and my level of understanding of Title V, albeit in laymen's terms, allowed me ask questions for which I had no preconceived answers.

After IRB approval from the University of Utah, I started with a letter and electronic invitation to UIHO Executive Directors and IHS employees to participate in an interview with me either in-person or by telephone, dependent on their location and my resources for travel. The most current and comprehensive contact information for UIHOs and IHS administrators was available through resource directories provided by the National Council of Urban Indian Health, the Indian Health Service, and the Urban Indian Health Institute websites. Using purposeful sampling, other key actors such as agency staff and community members were identified through recommendations and invited to interview. In order to reach saturation of Title V administrative stakeholders, I interviewed 15 participants.[2] This number of participants' represented the types of existing UIHO programs, the geographic diversity of the UIHP, and allowed for the inclusion of stakeholders identified working outside a characteristic UIHO site. I was mindful of the political implications of a government employee's participation as it is often the policy of federal agencies to defer interview requests to public information or

[2] Initial invitations for participation were sent to current UIHO directors, executive leadership in IHS, NCUIH, as well as past UIHO directors and managers, or approximately 40 interview requests

press releases. The confidential participation of all interviewees was held in accordance to the NASW Code of Ethics.

Data Collection

Document analysis began prior to the interviews by using scholarly articles, legislative and UIHO agency reports, review of newspaper coverage, and review of the IHCIA transcripts of hearings from 1974-1976; this information lends to the historical construction of 20th-century Indian health policy as well as a list of potential key informants. The second stage of data collection began after my January 2011 IRB approval with 4 months of qualitative, conversational interviews conducted in-person or by telephone. Purposive sampling as defined by Berg (2009) allows researchers to use *their special knowledge or expertise* about a group to select participants who best represent the group or population of study. I utilized my knowledge of the UIHO system to ensure Title V stakeholders were identified for participation. Though purposive sampling has its limitations because findings lack generalizability, it can produce results that may provide rich and textured descriptions of the participant's experience. This approach attempts to guarantee the opinions and attitudes of participants are reflected which allows for a greater understanding of Title V (Berg, 2009; Creswell, 2009; Marshall & Rossman, 2006).

Document analysis not only aided in the creation of my research questions but also the interview guide. As part of my qualitative inquiry, the information I discovered in the documents could be checked during interviews or supplement the questioning of participants. Using a SONY ICD-PX820 recorder with an OLYMPUS telephone pickup microphone, I recorded each phone interview and reviewed raw data prior to

transcription. I initially transcribed my data in order to understand the qualitative process and immerse myself in the IPA method, but because I was slow with typing script, I utilized a local transcription service beginning in the fall of 2011.

Data Analysis

I used IPA as a framework to explore my data as communities of meaning and to understand the policy artifacts. IPA identified the participant's artifacts through which their Title V understandings were expressed, communicated, and interpreted (Yanow, 2000, p. 27). From the stakeholder interviews, I clarified the types of meanings given Title V, and how these professionals demonstrate their understandings of the policy through shared communities of language, definitions, or the way in which health care services are provided.

I began with data reduction to organize and prepare the raw data, which included transcription of the audiotapes, typing my interview/field notes, and sorting the data by type (interview) or source (field notes). This step provided a general sense of the overall tone and context of the interviews and allowed me to check the transcripts for mistakes. Next, I read and reread the transcribed data to become familiar with what I was seeing and to record my overall impressions and ideas about the interviews. During this analysis of the transcriptions, I began a line-by-line coding of the data and looked for emerging themes. Coding line-by-line created my topics through identification of descriptive words similar to language from the literature and Title V policy, as well as any codes similar to my theoretical perspectives. I coded all of my emerging themes using a different color to represent independent themes, followed by categorization. Multiple themes were either merged or separated as appropriate. This analysis generated descriptors of interview

responses and themes that included detail towards Title V-specific references and language (Creswell, 2009, pp. 185-190).

Using Yanow's framework (2000), the last step in the analysis was a descriptive analysis and interpretation of meaning from the thematic artifacts identified during data coding. This was done by first identifying the emerging references of common points from my notes taken through observation, document analysis, and interview transcripts. Since the participants were all affiliated with administration of urban Indian health care, these factors categorized themselves because of the shared language used at all three points of analysis.

Dissemination of Information

I have selected the Multiple Article Path (MAP) format for my dissertation. The structure for MAP requires three distinct articles to create Chapters 2, 3, and 4 of the dissertation. I am proposing the following articles for those chapters.

Article One: Urban American Indian Health in the 21st Century

Chapter 2 is an overview of the establishment of the federal trust obligation that led to the construction of 20th century American Indian Health policy, including a review of federal policies that led to the creation of Urban Indian Health Organizations. I created a table of the federal policies that led to the construction of the Indian Health Care Improvement Act, P.L. 94-437. A significant piece of Chapter 2 (article one) examined the failed attempts to reauthorize the IHCIA prior to the ACA and how permanent authorization of IHCIA, now under Title X of Patient Protection and Affordable Care Act P.L. 111-148, places urban Indian health care as a permanent force to be reckoned and understood. I conducted a broad literature search in order to provide

an understanding of the current and historic statuses of health and health policies for urban Indians. Articles found through literature searches in PsychInfo, PubMed, Web of Science, and other social work and public health databases at the University of Utah were used to construct the health policies for American Indians. Document analysis was conducted from relevant hearings before U.S. Congressional Committees, such as the Senate Committee on Indian Affairs, population data from the U.S. Census, publications regarding policy recommendations from the American Public Health Association, the Urban Indian Health Institute, the National Council of Urban Indian Health, Indian Health Service, National Indian Health Board, and other health organizations identified as having interest in American Indian and/or public health policy, to construct the 20th century history. This article will be submitted for consideration to the American Journal of Public Health, the official journal of the American Public Health Association.

Article Two: Communities of Meaning: Interpreting the Impact of Title V on Urban Indian Health

Chapter 3 presents the communities of meaning brought forth from exploratory, conversational interviews conducted with the stakeholders who create, implement, or oversee Title V services. In the course of conducting interviews, I looked at agency, regional, and national agency documents regarding Title V as "artifact"--the concrete or metaphoric symbols in language, objects, or acts that are used or referred to for Title V. Utilizing IPA (Yanow, 2000) a review of policy and/or agency artifacts provided the breakdown of the varying forms of language, objects, or acts that characterize the meanings that Title V holds within the UIHP system; this lent to identification of the communities of meaning (UIHO leadership), which is a policy-relevant

group/community. This article (a) provides a stakeholder's view of Title V, and (b) describes their perspectives of meaning and how it is reflected in the service delivery or decision making for provision of health services in their UIHP agency. Ultimately, this chapter captures what service delivery looked like under Title V in 2011, and gives voice to UIHO. This article will be submitted for consideration to *AlterNative: An International Journal of Indigenous Peoples*, a multidisciplinary and peer-reviewed journal.

Article Three: Are Federal Health Policies for Urban American Indians Socially Just?

Chapter 4 identifies emerging issues and recommendations regarding Title V. Using TribalCrit as the theoretical framework (Brayboy, 2005), I identified how the voices of urban Indians are heard or represented in the federal health policies for American Indians. TribalCrit addresses the concepts of culture, knowledge, and power created through a Western or colonized perspective, and offers alternative ways of understanding through an indigenous lens the liminal space created by urban Indians (Brayboy, 2005). The origin of federal Indian policy was to assimilate or eradicate the indigenous inhabitants of the U.S. and dislocate them from their land and their socioeconomic, political, religious, and cultural existence. As each attempt by the U.S. government failed to reach its goal to address the "Indian problem," new policies replaced failed policies and moved towards an era of government support for self-determination and acknowledgment of the trust obligation, specifically for the provisions of health and welfare.

A critical examination of whether Title V renders the type of support necessary to raise the health status of urban Indian communities is offered. Have medical and mental health care, including health promotion and disease prevention activities, been created in the unique voice of urban Indians whereby their collective voice, through federal consultation, has been included in the authorization of health policy?

Understanding the political history and cultural need behind the creation of urban Indian spaces is crucial to understand how urban Indians formed a unique voice out of necessity, survival, and identity; a fundamental question that frames the federal relationship between the U.S. and American Indians is whether the tribe or individual member are self-determined, autonomous, and federally recognized political entities. Why the federal government would want to separate its federal trust obligation from American Indians living off-reservation is a strong political action deeply rooted in post-colonial federal policies of assimilation.

Globally, there are similar health inequalities of Indigenous peoples that can be linked to colonization and urbanization; utilizing a social determinants of health framework for analysis, I point out these health inequalities as largely the result of historical, social, and behavioral determinants, as well as the varied political and legal responses by the United Nations as compared to the U.S. history of Indian federal policy. I explore what political protection exists, or is needed, that allows UIHO to continue serving urban Indians. This article will be submitted for consideration to *The Journal of Indigenous Voices,* a peer-reviewed journal intended for those who work and live in indigenous and academic social work practice communities.

Conclusion

Sometime after the creation of the IHCIA, the conversation about Indian health went from raising the status of Indian citizens to the level of the general society to the need for united health care reform and health care financing. No longer is the conversation about service delivery. Thirty-two federally recognized (through Title V) urban Indian health organizations offer services with unique characteristics to their community; we have yet to begin to articulate how these programs engage clients in various cultural ways in order to promote health and disease prevention.

For this qualitative inquiry, I operated under the idea that urban Indian health care delivery that is linked to Title V has varied communities of meaning; that within the UIHOs, this linkage promotes the individual UIHP community-driven health outcomes, the types and provision of services to address the intended outcomes, that in combination are working to reduce health disparities experienced in the urban Indian communities. Whether Title V is key to these actions is discovered through my conversations with key Title V interviewees. As my educational study in qualitative methods is the first known inquiry of this sort in the urban Indian health care literature, I want it to be the developing basis for further research to understand relationship and function of service delivery, health outcomes, and federal urban Indian health policy. I understand that policy analysis can impact decision makers on that policy. However, this research is looking at the overall meaning of Title V, authorized nearly 36 years ago, within the urban Indian health communities.

The social work profession is a policy-driven profession because our practice is driven by the social policies that determine how we do our work, with whom, for how

long and how much, and to what end. Professionally, we challenge forms of social injustice and inequality experienced by vulnerable and oppressed peoples, such as issues of poverty and discrimination (National Association of Social Workers, 2008). Social welfare policies in the United States are developed for many reasons--response to social problems or issues, to bring relief during economic downturn, enforce social control, or to correct past injustices. For American Indians, their unique status as a minority group in American society is a result of history and of federal Indian policy; policy that not only recognizes Indian tribes as independent, political entities, but has also varied between regarding tribes as sovereign equals to attempts to eradicate, assimilate, or terminate tribes. As an indigenous woman, I am principally concerned with the health disparities disproportionately experienced in urban Indian communities; as an indigenous social work researcher, I am exploring the layers of social, political, and racial determinants that have contributed to the health conditions of a historically marginalized population. In so doing, I am contributing to the understanding of a unique racialized *and* politicized minority population--urban American Indians, who continue to disproportionately experience health disparities 36 years after the creation of a federal response to reduce the inequalities.

References

Belluck, P. (2009, December 2). New hopes on health care for American Indians. *The New York Times*. Retrieved December 17, 2009, from http://www.nytimes.com

Berg, B.L. (2009). *Qualitative research methods for the social sciences* (7th ed.). Boston: Allyn & Bacon.

Bergman, A.B., Grossman, D.C., Erdrich, A.M., Todd, J.G., & Forquera, R. (1999). A political history of the Indian health service. *The Milbank Quarterly*, *77*(4), 571-604.

Brayboy, B.M.J. (2005). Toward a tribal critical race theory in education. *The Urban Review*, *37*(5), 425-446.

Council on Social Work Education. (2009, November 4). *Update on reauthorization of the Indian health care improvement act.* Retrieved May 26, 2010, from http://www.cswe.org/CentersInitiatives/PublicPolicyInitiative13758/PolicyNews/25736.aspx?PS=2009.html.

Chinitz, J., & Christian, D. (Eds.). (2009). *An American debt unpaid: Stories of native health*. Health Rights Organizing Project. Northwest Federation of Community Organizations.

Creswell, J.W. (2009). *Research design: Qualitative, quantitative, and mixed method approaches* (3rd ed.). Thousand Oaks, CA: Sage.

Darder, A., & Torres, R. (2004). *After race: Racism after multiculturalism*. New York: New York University Press.

Denzin, N.K., & Lincoln, Y.S. (eds.). (2005). Sage handbook of qualitative research (3rd Ed.). Thousand Oaks: Sage.

Denzin, N.K., Lincoln, Y.S., & Smith, L.T. (Eds.) (2008). *Handbook of critical and indigenous methodologies*. Thousand Oaks, CA: Sage.

Dixon, M., & Roubideaux, Y. (Eds.). (2001). *Promises to keep: Public health policy for American Indians and Alaska natives in the 21st century.* Washington DC: American Public Health Association.

Forquera, R. (2001). *Issue brief: Urban Indian health*. Henry J. Kaiser Family Foundation.

Getches, D.H., Wilkinson, C.F., & Williams, R.A. (1993). *Federal Indian law: Cases and materials on federal Indian law* (3rd ed.). St. Paul: West Publishing Co.

Gibson, A.M. (1980). *The American Indian: prehistory to the present*. Lexington: D.C.

Heath and Company.

Gold, M. (1999). The changing US health care system: Challenges for responsible public policy. *The Milbank Quarterly*. *77*(1), 3-37.

Herrmann, B. (2009, August 28). Update on recovery act funds for education. *Indian Country Today*. Retrieved August 4, 2010, from http://www.indiancountrytoday.com/living/55747692.html

Indian Health Care Improvement Act of 1976, Pub. L. No. 94-437, § 501 et seq. 90 Stat. 1400 (1976).

Indian Health Care Improvement Reauthorization and Extension Act of 2009. (2009). In GovTrack.us. Retrieved May 26, 2010, from http://www.govtrack.us/congress/bill.xpd?bill=s111-1790&tab=summary

Indian Health Service. (2009 October). Trends in Indian health, 2002-2003 edition. Washington Government Printing Office.

Institute of Medicine. (2002). *Unequal treatment: Confronting racial and ethnic disparities in health care.* Washington, DC: National Academies Press.

Kaiser Family Foundation. (2010, March). *U.S. health care costs: Background brief*. Retrieved July 31, 2010, from http://www.kaiseredu.org/topics_im.asp?imID=1&parentID=61&id=358

Kaiser Health News. (2006, February 7). *President Bush releases fy 2007 budget proposal; $36B medicare spending reduction expected to have difficult approval process*. Retrieved September 17, 2010, from http://www.kaiserhealthnews.org/dailyreports/2006/february/07/dr00035249.aspx

Lambrew, J.M., Podesta, J.D, & Shaw, T.L. (2005). *Change in challenging times: A plan for extending and improving health coverage*. Health Affairs- Web exclusive. (2005, 23 March).

Lobo, S., & Peters, S. (Eds.) (2001). *American Indians and the urban experience*. Walnut Creek: Alta Mira Press.

Marshall, C., & Rossman, G. B. (2006). *Designing qualitative research* (4th ed.). Thousand Oaks: Sage.

Miranda, L. (2009, October 23). Lawmakers push health care reform in Indian country. Retrieved from http://colorlines.com/archives/2009/10/post_50.html. (2009, October 29).

National Association of Social Workers (2008). *Code of ethics of the national association of social workers*. Washington DC.

National Congress of American Indians and National Indian Health Board. (2006, February). *Reauthorization of the IHCIA*. Retrieved September 17, 2010, from http://www.ncai.org/ncai/advocacy/hr/docs/IHCIA_Fact_Sheet_NCAI_NIHB.pdf

New York Times. (2008, January 28). Editorial: Vetoing history's responsibility. *The New York Times*. Retrieved March 23, 2010, from http://www.nytimes.com/2008 /01/28/opinion/28mon3.html?_r=1&pagewanted=print

Office of Minority Health American Indian/Alaska Native Profile. (n.d.). Retrieved September 16, 2010, from http://minorityhealth.hhs.gov/templates/browse/aspx?vl=2&lvliD=52

Office of the Press Secretary. (2010, March 23). *Statement by the President on the Reauthorization of the Indian Health Care Improvement*. Retrieved September 17, 2010, from http://www.whitehouse.gov/the-press-office/statement-president-reauthorization-indian-health-care-improvement-act

Organisation for Economic Co-Operation and Development. (2010, June 29). *Growing health spending puts pressure on government budgets, according to OECD health data 2010*. Retrieved July 31, 2010, from http://www.oecd.org/document/11/0,3343, en_215 7136 1 _44315115_45549771_1_1_1_1,00.html

Renfrew, M.J. (2006). The 100% federal medical assistance percentage: A tool for increasing federal funding for health care for American Indians and Alaska natives. *Columbia Journal of Law and Social Problems. 40*(2), 173-227.

Rhoades, E.R. (Ed.). (2000). *American Indian health: Innovations in health care, promotion, and policy.* Baltimore: Johns Hopkins University Press.

Roubideaux, Y. (2004). A review of the quality of health care for American Indians and Alaska natives. The Commonwealth Fund (September 2004).

Savage, M.W. (2010, July 29). Obama to sign bill targeting violent crime in Indian reservations. *The Washington Post*. Retrieved July 29, 2010, from http://www.washingtonpost. com/ wp-dyn/content/article/2010/07/28/AR2010072805794.html

Schneider, A. (2005). Reforming American Indian/Alaska native health care financing: The role of Medicaid. *American Journal of Public Health*. *95*(5), 766-768.

Smith, L.T. (2006). The role of research in indigenous struggles for social justice. In N.K. Denzin & M. D. Giardina (Eds.), *Qualitative inquiry and the conservative challenge* (pp.151-174). Walnut Creek, CA: Left Coast Press.

Snipp, C. M. (2000). Selected demographic characteristics of Indians. From the text *American Indian Health: Innovations in Health care, Promotion, and Policy* (Ed. E.R. Rhoades.). Baltimore: Johns Hopkins University Press.

Smyer, T., Stenvig, T.E. (2007). Health care for American Indian elders: An overview of cultural influences and policy issues. *Home Health Care Management & Practice. 20*(1), 27-33.

Snyder Act of 1921, Public Law 67-85, 25 U.S.C. 13 (1921)

The Harvard Project on American Indian Economic Development. (2008). *The state of the native nations: Considerations under U.S. policies of self-determination.* New York: Oxford Press: Author.

Trombino, C. (2005). Changing the borders of the federal trust obligation: The urban Indian health care crisis. *Journal of Legislation and Public Policy*. *8*(1), 129-162.

Urban Indian Health Commission (2007*). Invisible tribes: Urban Indians and their health in a changing world.* Seattle: Urban Indian Health Commission.

Urban Indian Health Institute (2004). *The health status of urban American Indians and Alaska Natives: An analysis of select vital records and census data sources.* Seattle, WA.

Urban Indian Health Institute (2008). *Reported health and health-influencing behaviors among urban American Indians and Alaska Natives: An analysis of data collected by the behavioral risk factor surveillance system*. Seattle, WA.

U.S. Commission on Civil Rights (2003). *A quiet crisis: Federal funding and unmet needs in Indian country.* Washington, DC.

U.S. Commission on Civil Rights (2004). *Broken promises: Evaluating the Native American health care system.* Washington, DC.

Westmoreland, T.M., & K.R. Watson. (2006). Redeeming hollow promises: The case for mandatory spending on health care for American Indians and Alaska Natives. *American Journal of Public Health. 96*(4), 600-605.

Wilkins, D. (1992). Who's in charge of U.S. Indian policy? Congress and the supreme court at loggerheads over American Indian religious freedom. *Wicazo Sa Review*. *8*(1), 40-64.

World Health Organization. (2009, January 19). The financial crisis and global health: Report of a high-level consultation. Retrieved July 27, 2010, from http://www.who.int/topics/financial_crisis/financialcrisis_report_200902.pdf

Yanow, D. (2000). *Conducting interpretive policy analysis*. (Sage University Papers Series on Qualitative Research Methods, Vol. 47). Thousand Oaks, CA: Sage.

Zuckerman, S., Haley, J., Roubideaux, Y., Lillie-Blanton, M. (2004). Health service access, use, and insurance coverage among American Indians/Alaska natives and whites: What role does the Indian health service play? *American Journal of Public Health*, *94*(1), 53-59.

S. Rep. No. 94-133 (1975)

H.R. Rep. No. 94-1026 (1976)

CHAPTER 2

URBAN AMERICAN INDIAN HEALTH IN THE 21ST CENTURY:

ARTICLE 1

Introduction

In February 2006, President George W. Bush released his proposed budget for FY 2007. In line with his austerity policies, cuts were proposed to a slew of domestic, discretionary line items, most from health, science, and human service programs (Kaiser Health News, 2006). Among these recommendations came the complete elimination of the Urban Indian Health Program (UIHP), a line-item discretionary funded program within the IHS budget. Department of Health and Human Services (DHHS) officials, in justification of the President's proposed budget, said beneficiaries under UIHP were covered by other federally funded health and human services. Cutting urban programs amounted to a $33 million savings and the end of what the Bush administration viewed as funding of duplicative services and an unconstitutional practice of funding programs based purely on racial classification.

Under the Bush Administration, the Department of Justice and the Office of Management and Budget pushed a constitutional argument that divided resources in the proposed FY2007 budget from federally recognized tribal governments and the enrolled tribal members who live off-reservation. Potentially, this action would forfeit federal obligation to provide health care services through Urban Indian Health Organizations

(UIHOs) -- since providing federal dollars for resources to American Indians living in urban areas would be unconstitutional if those dollars are granted based on "race" or "ethnicity." It appeared that federal lawmakers were creating new ways to continue the legacy of the federal policy of assimilation, thereby eliminating any federal obligation to American Indians living off-reservation. Today, there is a renewed interest in Indian policy with the Obama presidency making efforts to address a critical lack of federal obligation for Indian treaty rights or enforcement of existing federal Indian policies in the areas of education, housing, law enforcement, and health care (National Congress of American Indians, 2012; White House, 2010).

The Indian Health Care Improvement Act (IHCIA) was permanently authorized in the March 2010 passage of the Patient Protection and Affordable Care Act, P.L. 111-148 (ACA). Within the IHCIA is Title V: Health Services for Urban Indians; the purpose of Title V is the establishment of programs in urban areas to make health services more accessible to urban Indian communities. With the permanency of Title V under this Act, UIHOs enter a new political arena at the federal level for budget and policy consultation on behalf of the urban Indian populations served and for the population that has not accessed care, thereby raising the issue of accountability and awareness of federal funding to accomplish the intent of Title V.

To understand the intent and impact of federal Indian Health policies for the 21st century, we must recognize what effect centuries of government attempts to solve its "Indian problem" has had on Indian communities--on the reservations and in the expanding urban Indian communities. A long history of reversal of federal Indian policies that either supported self-determination or programs of assimilation has created a

lost fundamental meaning and recognition of the federal trust responsibility to provide health care to all Indians regardless of location. This article looks at how the federal trust obligation to provide health care to all AI/AN has adapted to the growing urban Indian population.

Reality of American Indians

The reality of 21st century American Indians should be understood by its various social, political, and economic marginalization or determinants and not the stereotypes that surround this contemporary population--that American Indians live on reservations, receive government or welfare handouts, and whose economic and welfare prosperity is provided by their tribe or tribal casino.

Demographics

In the 2010 Census, American Indians (AI) and Alaska Natives (AN), either alone or combined with one or more other races, numbered 5.2 million or 1.7% of all people in the U.S. The first time individuals were presented with the option to self-identify with more than one race was the 2000 Census, and this option continued with the 2010 Census.

Just as the U.S. population has become more urban, so too have American Indians. If we look at just the native population that identified as AI/AN only in the 2010 Census, 67% of this population is living away from federal or state recognized Indian/Native areas; while 92% of AI/AN who identified in combination of one or more other races live outside native areas. In other words, 78% of all AI/AN alone or in combination live away or off-Indian/Native lands (US Census, 2012). Just looking at the policy agenda of the National Congress of American Indians, it is clear that tribal

governments face an extensive range of political issues: tribal governance, community development, health and human services, land rights and resources, and other specific tribal and cultural concerns.

Economic concerns, educational attainment, and health disparities exist in American Indian communities significantly greater than for members of the general U.S. population. In 2010, 15% of the general U.S. population were living in poverty, compared to 28% of all AI/AN. Three quarters of all AI/AN over the age of 25 have obtained a high school degree/equivalency compared to the general population at 86% completion; even fewer AI/AN go on to earn a bachelor's degree or higher at 13%, compared to the general population rate of 28% (2010 Census Summary, 2012). The Indian population continues to experience significant health disparities compared with the general population, and now chronic diseases are on the rise, creating more challenges for the people and the system (Roubideaux, 2004). Indian health systems continue to try to meet the federal trust responsibility to provide health care for AI/AN despite significant shortfalls in funding, resources, and staff.

Federal Trust Relationship

The history of tribal and U.S. relations begins pre-Constitution and is a complex history of federal support established through the unique legal relationship between the United States government with federally recognized tribal governments set forth in constitution, treaties, statutes, executive orders, and court decisions. This relationship continually changed as the need for westward expansion by a new U.S. proceeded into Indian Country. Known as the Formative Years between 1789-1871 (Getches, Wilkinson, & Williams, 1993; Prucha, 1970), the postcolonial era federal Indian law and

policy moved beyond regulating a relationship built on trade or a doctrine of discovery, to management principles that advanced both U.S. development, and established the doctrine of federal trust responsibility. By the turn of the 20th century, the U.S. Government had moved away from its policies of removal and treaty making with American Indian tribes towards policies aimed at civilizing and assimilating Indians (Figure 2.1).

This federal trust responsibility continues to change, but now on an economic basis under the pretext of our current federal Indian policy of self-determination. The era of self-determination is said to have begun with the Indian Reorganization Act of 1934, but it obtained its true impetus when President Nixon called for self-determination without termination in his 1970 Indian Policy Statement (Dixon & Roubideaux, 2001; Rhoades, 2000; Trahant, 2010). Nixon called for the end of termination policies and greater scope for self-determination by tribes on reservations, through tribal self-determination and tribal control and operation of federal programs. Self-determination is a principle that people have the right to govern themselves without interference; for American Indians, this allows tribes to directly manage and operate their tribal government programs with federal funding. The Nixon Administration recognized the alleviation of severe economic, education, and health problems experienced by AI/AN communities and reservations could be achieved through federal assistance and a restoration of federal trust responsibility, including an increase in the financial support of the Indian Health Service and acknowledgement/attention to the need to help urban Indians (Forquera, 2001; Rhoades, 2000; Trahant, 2010). Nixon's statement brought a recognition and understanding of Indian Country as Indian peoples as nations, not

minorities (Harvard Project, 2008) and that the federal trust obligation extended to all American Indians and Alaska Natives regardless of location in the U.S.

IHCIA and Title V

The one federal trust responsibility remaining from treaty obligations and federal statutes was to provide health care to members of federally recognized tribes (Forquera, 2001). Introduced as S. 522 in 1975, the Indian Health Care Improvement Act (IHCIA) of 1976 addressed the continuing lag of Indian health status behind that of the general population (Dixon & Roubideaux, 2001; Forquera, 2001). The Act's intent was to provide "the highest possible health status to Indians and to provide existing Indian health services with all resources necessary to effect that policy" [25 U.S.C. § 1602]. Until IHCIA, the Snyder Act of 1921 was the principle legislation authorizing health care services to American Indian as relief of distress and conservation of health. To meet its goal, IHCIA was designed to increase the number and quality of Indian health services while improving the participation of Indians in planning and providing those services. Title V of the Act established a separate program for urban Indians that did not expand the role of existing Indian health services into cities; rather, it encouraged urban Indian groups to form nonprofit corporations to contract with the Indian Health Service; a likeness of the Neighborhood Health Center initiatives of President Johnson's Great Society programs (Forquera, 2001). Initially contracts were designed to help the urban communities to create information and referral networks for health, but those cities that had already established urban Indian health centers were given federal funds to enhance or expand their clinical services.

Urban American Indians

Why are there urban Indians? This status is the direct result of the series of federal policies during the 1950s that purposefully relocated American Indians and Alaska Natives to cities with the promise of employment and education opportunities for their families, thereby promoting the continued federal policies of assimilation of Indians into the general, White American society (Dixon & Roubideaux, 2001; Forquera, 2001; Rhoades, 2000). Though assimilation and termination acts were intended to destruct tribalism, there was a growing tribal consciousness among tribal people both on and off reservation; termination did not mean termination of identity or cultural ties, but a recognition that control of Indian policy and lasting guarantees of sovereignty would assure tribal survival in the United States. The effects of termination on tribal economies, society, and health were another demoralizing blow to communities that were still rebuilding from decades of policies that created cultural, economic, health, and educational deprivation.

With federal trust relationships ending, so were federal programs and assistance to tribes. The period of termination was the beginning of the dramatic transformation of Indian country from reservation to urban populations across the U.S. An active policy of Indian relocation was implemented so that reservation Indians, either deliberately encouraged or forced by the economic realities of the reservation, could relocate to major urban areas for vocational training and better employment opportunities. BIA field relocation offices opened across the nation in Denver, Salt Lake City, Oakland, Chicago, Seattle, Oklahoma City, Los Angeles, San Jose, Dallas, San Francisco, Tulsa, and

Cleveland (Harvard Project, 2008). These would become the sites of Title V funded urban Indian health programs beginning in the late 1960s (Figure 2.2.).

Health Status of Urban Indians

Urban Indian health disparities exist today as they did 35 years ago at the time of the passage of IHCIA, and urban Indians still experience greater health disparity rates than the majority population (Indian Health Services, 2009). In *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Institute of Medicine, 2002), the Institute of Medicine (IOM) defined disparity to be any difference not due to health status or preferences for health care services, and that those differences are considered disparities if the differences are due to the operation of health care systems, the legal climate, discrimination, and other socioeconomic factors; in other words, the social determinants of health. The report went on to highlight that greater difference in quality of health exists for racial/ethnic minorities in the United States. Differences in health status between the majority population and American Indian population relate to the social, economic, and historic factors that differentiate the groups; and even with the creation of a health policy for American Indians, the policy only offers support to the Indian communities to address their disparities and not the determinants of health.

Current literature on the health status of urban Indians consistently reveals a connection between the high levels of risk factors/health issues and poverty (Urban Indian Health Institute, 2008). Reliable health statistics on urban Indians are scarce because this demographic has been insufficiently researched and its community members are often misclassified on vital records as belonging to other races or ethnicities. Health disparities identified in the research highlights the prevalence of chronic disease, the

structure and use of health care services, and an AI/AN marginalized socioeconomic status (U.S. Commission on Civil Rights, 2003, 2004; Urban Indian Health Institute, 2004, 2008). Studies from the Urban Indian Health Institute have found that urban AI/AN suffer from significant health disparities compared with the general population. Common health disparities to the urban Indian population are diabetes, depression, cardiovascular disease, HIV, and obesity (Urban Indian Health Institute, 2008). These disparities include higher rates of tobacco use, infant mortality, later prenatal care, interpersonal violence, attempted suicide, and deaths due to diabetes, accidents, and chronic liver disease.

A long history of reversal of federal Indian policies that either supported self-determination or programs of assimilation has created a lost fundamental meaning and recognition of the federal trust responsibility to provide healthcare to all Indians regardless of location (Table 2.1). Even though more people who are Indian live in cities than on reservations, federal policy toward Indian affairs continues to focus its information-gathering and financial resources on reservation communities (Urban Indian Health Institute, 2004). The Indian health care system is as complex as the creation of federal Indian law and policy. Today's Indian health care delivery system is more than just IHS--it has become a collaboration of federal, state, local, and tribal health systems (Dixon & Roubideaux, 2001; Forquera, 2001; Rhoades, 2000; Roubideaux, 2004; Zuckerman, Haley, Roubideaux, & Lillie-Blanton, 2004).

As the conversation in the 1970s was about Indian health raising the health status of **all** American Indians and the creation of programs to address access, today, the discussion among U.S. policymakers has switched to health care reform and health care

financing (Gold, 1999). In addition, IHCIA went without its congressional review for reauthorization from 1992 to 2009. During these 17 years, IHCIA was ignored for reauthorization and the U.S. health care delivery system was revolutionized while the Indian system for health care was not (Lambrew, Podesta, & Shaw, 2005; National Congress of American Indians and National Indian Health Board, 2006). IHCIA reauthorization proposals had been introduced into four Congresses during that 17 year stretch; however, none passed for various reasons of economy, interest, language of the bill, or threat of Presidential veto (New York Times editorial, 2008). Access to health care for American Indians includes a mix of private and public sources not unlike those for other Americans. So what does permanent authorization of this system as legislated by IHCIA mean today?

What's Next? The Permanent Reauthorization of IHCIA and Title V in the ACA

> I am absolutely committed to moving forward with you and forging a new and better future together. It's a commitment that's deeper than our unique nation-to-nation relationship. It's a commitment to getting this relationship right, so that you can be full partners in America's economy, and so your children and grandchildren can have an equal shot at pursuing the American dream. [spoken by President Barack Obama, March 23, 2010]

Within the Affordable Care Act (ACA), the Indian Health Care Improvement Act was given permanent reauthorization. The IHCIA authorizes the Indian Health Service to provide health care services to AI/AN; Title V of the IHCIA extends those provisions to urban American Indians. Because the IHCIA was included (as Title X) in the ACA, the IHCIA is now a permanent law that now authorizes new programs within IHS to meet its obligation to raise the health status of all AI/AN to the highest level. Ultimately, the ACA

will extend the authorizations of appropriations for IHCIA programs indefinitely (Heisler & Walke, 2010).

How IHCIA Got Permanent Authorization

"Clearly, the federal government has not fulfilled its trust responsibility to provide quality health care to you, your family and your neighbors in Indian Country. The new law begins to change that sad fact." Sen. Byron L. Dorgan [excerpt from the Dear Tribal Leaders letter sent April 14, 2000, by the Chairman of the Senate Committee on Indian Affairs regarding the permanent reauthorization of the IHCIA in the passage of the ACA].

Through a reauthorization process, it is customary for Congress to look at major federal law every 5 to 7 years to update and modernize policy that reflects the evolution of community needs and conditions (National Indian Health Board, 2006). IHCIA had gone without this Congressional review since 1992, and since 2000 had been in continuation. Continuation of federal authority means to continue the federal funding of Indian health care services; this ability to provide continuation stems from the Snyder Act of 1921.

As the conversation about Indian health went from raising the health status of all American Indians (at time of the enactment of IHCIA) to the creation of programs to address access, the dominant society conversations have switched to health care reform and health care financing. In the 17 years span that IHCIA went without reauthorization, the American health care delivery system was revolutionized while the Indian system for health care was not (Lambrew, Podesta, & Shaw, 2005).

Indian health care policy issues became part of the Obama Administration's overall health care overhaul. Kathleen Sebelius, Secretary of the U.S. DHHS, publicly promised tribes that the President supported special consideration for American Indians in terms of health care reform (Miranda, 2009). Not since the creation of IHCIA had an

Administration so publicly acknowledged the overdue need to bring improvements to the Indian health system and address the extreme health disparities that afflict Indian communities. This passage brings Indian health care into the national reform conversation as well as the placement of urban Indian health organizations into the political arena.

President Obama signed the bill (P.L. 111-148) into law March 23, 2010. In a statement released by the White House, President Obama declared,

> I signed into law the Patient Protection and Affordable Care Act, the health insurance reform bill passed by Congress ... [T]his bill permanently reauthorizes the Indian Health Care Improvement Act, which was first approved by Congress in 1976… I believe it is unacceptable that Native American communities still face gaping health care disparities. Our responsibility to provide health services to American Indians and Alaska Natives derives from the nation-to-nation relationship between the federal and tribal governments. With this bill, we have taken a critical step in fulfilling that responsibility by modernizing the Indian health care system and improving access to health care for American Indians and Alaska Natives [Office of the Press Secretary, 2010].

With the permanent authorization of IHCIA within the ACA, urban Indians, at least those covered by Title V, are now part of the political arena and given new status for consideration. The federal obligation to provide health care is in relationship to tribes, not to individual tribal members/citizens. That there is no carryover of treaty rights to the individual is most likely the remnants of assimilation.

What the ACA Does to Urban Indian Health

Whereas urban Indians do not enjoy self-determination as the reservation-based tribal governments do (The Harvard Project on American Indian Development, 2008), with permanent authorization of the IHCIA, urban Indian centers may now build community capacity through political and economic power.

UIHOs have expanded program authority and will be responsible for implementing key aspects of service delivery in the ACA, including ability to expand service delivery outside their (federally recognized) urban center. The ability to expand beyond where they have been providing services (and to whom) means UIHOs have the potential to become community health centers (CHC), thereby placing the urban Indian health delivery system into a larger community-based system of health care delivery for all Americans. This means that UIHOs are more likely to serve an even greater range of eligible clients (including eligible non-Native clients for CHC services) than they have historically, more than "the general IHS health care programs, including not only members of federally recognized tribes but also members of terminated or state recognized tribes, as well as their children and grandchildren" (Heisler & Walke, 2010).

Much of the new programs provided by ACA, like expansion of Medicaid, increased funding for community health centers, and elimination of coverage discrimination due to pre-existing conditions, will be utilized by the AI/AN population because these programs are for all eligible U.S. citizens regardless of race/ethnicity. However, in the UIHO system, some agencies may be eligible to purchase coverage for their employees from the Federal Employees Health Benefits Program, more UIHOs regardless of their level of care could purchase goods and services through federal sources of supply (like reduced cost medications), and grants can now be made for the development and implementation of health information technology, telemedicine, and related infrastructure (Heisler & Walke, 2010).

Permanency also diminishes the threat of elimination of the UIHP, whereby the type of derailment proposed by the Bush Administration in 2006 would be difficult.

However, we are in the midst of an impending U.S. Presidential election. The ACA was not openly received by Republican Party members of Congress and since its passage, there has been political action and dialogue to repeal the ACA. A complete repeal requires two-thirds majority vote from both sides of Congress and in light of the political atmosphere since Obama became President, this is highly unlikely today. Nevertheless, in 2011, a Michigan Republican talked about "significant bipartisan support" to repeal the ACA. He went on to say, "… (we) will demonstrate the need to repeal this law and replace it with common sense reforms that lower costs and increase accessibility to healthcare without increasing government" (Trahant, 2011). I see a problem for the IHCIA if the ACA were repealed because out goes the permanent authorization status and any possibility for continuity of federal appropriations to the UIHO. Who will guarantee the protection of the federal obligation, or return back to a stand-alone IHCIA, for AI/AN health care if the ACA were repealed?

Funding Issue Not Addressed by ACA

> Beyond the stark rhetoric however is a practical question. Will the new Republican majority support stable funding of the Indian Health Care Improvement Act? ...Republicans promised a frugal government. If that's what they really want, then the Indian health system should be fully funded because it's the most efficient health care delivery system in the country.
>
> [Mark Trahant, Indian Country Times, January 3, 2011]

What will the health of urban Indians be if Congress continues to allocate just over 1% of the federal annual appropriations for Indian health? The urban Indian population along with the growing cost of health care continues to rise at rates far beyond the government's funding. Nixon's Indian policies viewed American Indians not as minorities but as members of nations, and Nixon's acknowledgment of urban Indians clarified federal obligation to extend its trust responsibility off-reservation. Nixon wrote,

"As a first step toward helping the urban Indians, I am instructing appropriate officials to do all they can to ensure this misunderstanding is corrected" (Trahant, 2010). In fiscal year 2006, the same year President Bush proposed elimination of urban Indian health for the FY 07 budget, Congress spent 32.7 million dollars on the Urban Indian Health Program, which amounts to approximately 1% of IHS's $3 billion annual budget (Urban Indian Health Commission, 2007). In 2005, the UIHO served roughly 100,000 Indians in their centers. In the 21st century, it is funding, more so than the IHCIA, that is essential to the livelihood of UIHO's. Reliance on federal dollars has produced a system that is insufficient and unreliable and is associated with ongoing health disparities (US Commission on Civil Rights 2003, 2004; Westmoreland & Watson, 2006). Most Indian health policy literature garners agreement on two issues: adequate funding and adaptation of policy goals for urban Indian Health (Roubideaux, 2004; UIHI, 2011; Warne, 2009).

Conclusion

Have the assimilation policies of the United States government succeeded in not only displacing Indians from their culture but also of the federal trust responsibility to provide services to the country's Indigenous inhabitants? The only people in the United States who have an inherent, legal right to health care provisions from the federal government are American Indians. The ACA extends health coverage to millions of people who otherwise have no coverage or ability to pay; some of the key provisions are expansion of health coverage, improving the access to care, and provisions to address health disparities. One of these provisions related to health disparities was the permanent authorization of all of the IHCIA. Permanent authorization eliminates the need for Indian

health organizations and tribal leadership to ask Congress every few years for funding (Henry J. Kaiser Family Foundation, 2010).

The trust responsibility of the federal government to provide health care to AI/AN is through the Indian Health Service. Trust is built on accountability. I hope you can trust if a person makes a mistake, because as humans we will, that the person will be accountable for the mistake. Just as Gilbert and Terrell (2010) describe an understanding of policy formulation from an institutions perspective, an analytical perspective, and a political perspective, so too must federal Indian health policies be viewed at the interface of these three elements. Federal Indian policy overwhelmingly focuses on tribal government and reservations rather than on American Indian individuals regardless of where they live. It can be argued that individual Indians who live off-reservation still remain Indian and as such, treaty rights presumably stay with their identity and status. However, urban Indians may find themselves cut off from support systems and health and welfare services that are provided on their tribal reservation. The relative lack of tribal services for off-reservation tribal people raises a fundamental question about the rights and treaties upon which federal assistance to Indians is implied, and the lack of recognition that it was federal policy that created the status of urban Indians.

ERA	Assimilation	Reorganization	Termination	Self-Determination
Years as Official Policy	Late 1800s-Early 1900s	1920s to 1950s	1950s to 1960s	1970 to… ?

Figure 2.1: Federal Indian Policy Eras

Figure 2.2: Map of the 34 federally recognized sites for Urban Indian Health Organizations (Source: UIHI, 2012)

Table 2.1: Chronology of Events in Urban American Indian Health Policy (Source: Getches, Wilkinson, & Williams, 1993; Shelton, 2004; Trahant, 2010)

YEAR	EVENT	DESCRIPTION
1921	Snyder Act	Establishes federal authority for provision of funds "for the benefit, care and assistance . . . and for the relief of distress and the conservation of health . . . for Indian tribes throughout the United States."
1928	Meriam Report	The report states, “the health of the Indians compared with that of the general population is bad.”
1934	Indian Reorganization Act	Reversed the Allotment Act that broke up Indian land and established Indian tribes to create formal government constitutions in order to increase tribal powers of government
1950s	Termination and Relocation	U.S policy terminates the government-to-government relationship with tribes, thereby ending trust obligation to provide care or services; relocation to urban areas by American Indians; both these events intended to further assimilation
1954	Transfer Act	Creation of the Indian Health Service
1970	Nixon speech	Introduces new era of federal Indian policy with inclusion of Indians in creating Indian policy
1974	American Indian Self-Determination and Education Assistance Act	Tribes allowed to contract for health care and other services previously provided by federal government
1976	Indian Health Care Improvement Act	To provide access to health care and help raise the health status of American Indians and Alaska Natives to the parity of the general society.
1980s	Elimination of UIHP funding	President Reagan eliminates UIHP
2006	Proposed elimination of UIHP	Department of Justice deems appropriations to UIHP unconstitutional because service delivery based on “race”
2010	Patient Protection and Affordable Care Act	IHCIA included in the ACA under Title X, giving it permanent reauthorization

References

Dixon, M., & Roubideaux, Y. (Eds.). (2001). *Promises to keep: Public health policy for American Indians and Alaska natives in the 21st century.* Washington DC: American Public Health Association.

Forquera, R. (2001). *Issue brief: Urban Indian health*. Henry J. Kaiser Family Foundation.

Getches, D.H., Wilkinson, C.F., & Williams, R.A. (1993). *Federal Indian law: Cases and materials on federal Indian law* (3rd ed.). St. Paul: West Publishing Co.

Gilbert, N., & Terrell, P. (2010). *Dimensions of social welfare policy.* Pearson

Gold, M. (1999). The changing US health care system: Challenges for responsible public policy. *The Milbank Quarterly*, *77*(1), 3-37.

Heisler, E. J., and Walke, R. (2010). Indian health care improvement act provisions in the patient protection and affordable care act (P.L. 111-148). Congressional Research Service Report for Congress, March 30, 2010.

Henry J. Kaiser Family Foundation. (2010, September). *Health reform and communities of color: Implications for racial and ethnic health disparities*. Facts on Health reform newsletter. Menlo Park: The Henry J. Kaiser Family Foundation.

Indian Health Service. (2009, October). Trends in Indian health, 2002-2003 edition. Washington Government Printing Office.

Institute of Medicine. (2002). Unequal *treatment: Confronting racial and ethnic disparities in health care.* Washington, DC: National Academies Press.

Lambrew, J.M., Podesta, J.D, & Shaw, T.L. (2005). *Change in challenging times: A plan for extending and improving health coverage*. Health Affairs- Web exclusive. (2005, 23 March).

Miranda, L. (2009, October 23). Lawmakers push health care reform in Indian country. Retrieved from http://colorlines.com/archives/2009/10/post_50.html. (2009, October 29)

National Congress of American Indians. (2012). *Fiscal Year 2013 Indian Country Budget Request: Our trust. Our people. Our America.* Washington, DC: Author.

National Congress of American Indians and National Indian Health Board. (2006, February). *Reauthorization of the IHCIA*. Retrieved September 17, 2010, from http://www.ncai.org/ncai/advocacy/hr/docs/IHCIA_Fact_Sheet_NCAI_NIHB.pdf

New York Times. (2008, January 28). Editorial: Vetoing history's responsibility. *The*

New York Times. Retrieved March 23, 2010, from http://www.nytimes.com/2008 /01/28/opinion/28mon3.html?_r=1&pagewanted=print

Patient Protection and Affordable Care Act, Pub. L. No. 111-148, §2702, 124 Stat. 119, 318-319 (2010).

Prucha, F.P. (1970). American Indian policy in the formative years: the Indian trade and intercourse acts, 1790-1834. Lincoln: University of Nebraska Press.

Office of the Press Secretary. (2010, March 23). *Statement by the President on the Reauthorization of the Indian Health Care Improvement*. Retrieved September 17, 2010, from http://www.whitehouse.gov/the-press-office/statement-president-reauthorization-indian-health-care-improvement-act

Roubideaux, Y. (2004). A review of the quality of health care for American Indians and Alaska natives. The Commonwealth Fund (September 2004).

Rhoades, E.R. (Ed.). (2000). *American Indian health: Innovations in health care, promotion, and policy.* Baltimore: Johns Hopkins University Press.

The Harvard Project on American Indian Economic Development. (2008). *The state of the native nations: Considerations under U.S. policies of self-determination.* New York: Oxford Press: Author.

Trahant, M.N. (2010). The last great battle of the Indian wars: Henry M. Jackson, Forrest J. Gerard and the campaign for the self-determination of American Indian tribes. Fort Hall: The Cedars Group.

Trahant, M. (2011). Indian health care a GOP target in the new Congress. Indianz.com retrieved from http://64.38.12.138/News/2011/000008.asp

U.S. Census Bureau. (2012, January). *The American Indian and Alaska Native Population: 2010 census brief*. Retrieved March 22, 2012, from http://www.census.gov/prod/cen2010/briefs/c2010br-10.pdf

White House Tribal Nations Conference Progress Report. (May 14, 2010). *Forging a new and better future together.* Retrieved March 2012 from http://www.whitehouse.gov/sites/default/files/rss_viewer /tnc_progress_report.pdf

Urban Indian Health Commission (2007*). Invisible tribes: Urban Indians and their health in a changing world.* Seattle: Urban Indian Health Commission.

Urban Indian Health Institute (2008). *Reported health and health-influencing behaviors among urban American Indians and Alaska Natives: An analysis of data collected by the behavioral risk factor surveillance system*. Seattle, WA.

Urban Indian Health Institute (2004). *The health status of urban American Indians and Alaska Natives: An analysis of select vital records and census data sources.* Seattle, WA.

Urban Indian Health Institute (2011, April). Actualizing health care reform for urban Indians: an action plan from the urban Indian health summit. Seattle: Urban Indian Health Institute.

U.S. Commission on Civil Rights (2003). *A quiet crisis: Federal funding and unmet needs in Indian country.* Washington, DC.

U.S. Commission on Civil Rights (2004). *Broken promises: Evaluating the Native American health care system.* Washington, DC.

Warne, D. (2009). Ten Indian health policy challenges for the new administration in 2009. *Wicazo Sa Review*, *24*(1), 7-23.

Westmoreland, T.M., & K.R. Watson. (2006). Redeeming hollow promises: The case for mandatory spending on health care for American Indians and Alaska Natives. *American Journal of Public Health. 96*(4), 600-605.

Zuckerman, S., Haley, J., Roubideaux, Y., Lillie-Blanton, M. (2004). Health service access, use, and insurance coverage among American Indians/Alaska natives and whites: What role does the Indian health service play? *American Journal of Public Health*. *94*(1), 53-59.

CHAPTER 3

COMMUNITIES OF MEANING: INTERPRETING THE IMPACT OF TITLE V ON URBAN INDIAN HEALTH ORGANIZATIONS: ARTICLE 2

Introduction

This article presents the communities of meaning discovered through analysis of exploratory, conversational interviews conducted with Title V stakeholders who create, implement, or oversee Title V services at Urban Indian Health Organizations. In the course of conducting interviews, I looked at agency, regional, and national agency documents regarding Title V as "artifact"—which is the concrete or metaphoric symbols in language, objects, or acts that are used or referred to for Title V.

During preparation for my dissertation proposal, during the document and observation stages, the IHCIA was finally given Congressional reauthorization. I had been preparing to ask about the reasons for failure to reauthorize the IHCIA for 17 years, or how UIHO language was always a sticking point in the congressional hearings. Then, P.L. 111-148, the Affordable Care Act or ACA, was introduced and pushed through, thereby giving IHCIA and Title V permanent authorization. With Title V placement in the ACA, for the first time, urban Indians were given the same status or position for consultation as tribal health. From this came questions about how stakeholders were made aware of the ACA positioning and how the passage of ACA was affecting service

delivery (some agencies reported medical record upgrades, or ability to provide health care to employees, or the payment changes), especially to these agencies that are Community Health Centers funded by federal 330 contracts, or Title V-based Federal Qualified Health Centers.

Utilizing Interpretive Policy Analysis (Yanow, 2000), a review of policy and/or agency artifacts provided the breakdown of the varying forms of language, objects, or acts that characterize the meanings that Title V holds within that policy-relevant group/community, and consequently, these communities of meaning were identified during interviews with stakeholders. This article (a) provides an understanding about Title V and urban Indian health, and (b) describes perspectives of meaning about how that is reflected in the service delivery or decision making for provision of health services to urban Indian communities. Ultimately, this article captures what Title V service delivery looked like in 2011, and gives stakeholders the opportunity to explain or define their service delivery model afforded by Title V.

Literature Review

According to 2010 Census data, American Indians and Alaska Natives (AI/AN), either alone or combined with one or more other races, numbered 5.2 million or 1.7% of all people in the U.S. The first time individuals were presented with the option to self-identify with more than one race was the 2000 Census, and this continued with the 2010 Census. Just as the United States is becoming more metropolitan or urban, so too are American Indians. Of the native population that just identifies as AI or AN only in the 2010 Census, 67% are living away from federal or state recognized Indian/Native areas; while 92% of AI/AN who identified in combination of one or more other races live

outside native areas. In other words, 78% of all AI/AN alone or in combination live away or off-Indian/Native lands (U.S. Census, 2012).

The U.S. federal government trust obligation to citizens of federally recognized tribal Nations is the direct result of centuries of government relations and treaties between tribes. One of these obligations is to provide health care services; the legal authority that establishes this provision is the Indian Health Care Improvement Act, P.L.94-437, or IHCIA. Title V of the IHCIA extends the federal responsibility of making health services accessible to AI/ANs living in designated or recognized urban areas. Indian Health Service (IHS) has the federal authority to enter into contracts with urban Indian health organizations (UIHOs) to assist the IHS provision of services to off-reservation Indian communities (IHCIA, 1976).

Established through Title V of the IHCIA, there are currently 34 UIHOs that are not-for-profit (501c-3 status) community health centers (Figure 2.2). These centers provide a range of culturally appropriate services, ranging from the provision of outreach and referral services to the delivery of comprehensive ambulatory health care, and everything in-between: medical services, dental services, alcohol and drug abuse prevention, education and treatment, AIDS and sexually transmitted disease education and prevention services, mental health services, nutrition education and counseling services, pharmacy services, health education, optometry services, social services, and home health care. Fifteen of the programs are designated as Federally Qualified Health Centers (FQHC) and provide services to Indians and non-Indians. Eighteen (18) additional cities have been identified as having an urban population large enough to support an Urban Indian Health Program (Indian Health Service, 2012).

The number of AI/AN receiving services and care at UIHO annually varies in estimates from 138,000 (Indian Health Service, 2012; National Council of Urban Indian Health, 2012) to nearly 150,000 clients (Urban Indian Health Institute, 2012). Funded at 1% of the entire Indian Health Service budget, in areas that according to Census 2010 data are occupied by 1.2 million AI/ANs (U.S. Census, 2012), UIHOs are only able to serve a small percentage of the population with an estimated per capita cost of less than $275.00 (National Council on Urban Indian Health, 2012). The FY 2010 Indian Health Service budget was $4.1 billion, and the Urban Indian Health Program budget was $43 million dollars (Northwest Portland Area Indian Health Board, 2010)

Compared to other federally obligated per capita spending for health care, urban Indians receive less funding for care than American Indians who receive care from their reservation or tribal based clinics (Figure 3.1).

Strategy of Inquiry

Unlike a traditional policy analysis (Karger & Stoesz, 2010) that looks to understand whether a policy is fulfilling its purpose (assumptions about facts or values), or to identify information essential to crafting new policy, interpretive policy analysis (IPA) explores the symbolic relationship and implied knowledge about a policy. Public policy is often created in the language and context understood by the person or people responsible for writing the legislation. Whereas policy makers deal with a political or social issue their way, IPA seeks to understand how the people deal with the same issue in their expressions or symbols of language. The meaning of the policy comes from the values, feelings, or beliefs expressed and how those meanings are communicated to, and understood by, various audiences who are affected by the policy.

According to Yanow (2000), different communities of meaning provide alternative views in which there is no single "correct" formulation of a policy statement; thus, the context of the historic, cultural, and social values of polices influence their creation, implementation, and are context-specific. Therefore, we must unlock the perspectives of stakeholders to provide the meanings that are hidden and missing from the assumptions of policymakers. An interpretive approach opens up the dynamics (or complexities) of the policy process by recognizing the interaction of ideas within (in this case Title V-funded agencies) which the policies/legislation are located. Therefore, this approach challenges the dominant framework of the policy text. In urban Indian health, what are the implications of these meanings for the implementation of Title V?

Interpretative policy analysis is intricately part of its research methods. This framework includes the use of document analysis (policy artifacts such as transcripts of congressional hearings, legislation, or agency documents), observation, and conversational interviews. IPA assists in my identification of the groups of people (known as *communities*) who might share understandings about policy ideas and language that would be different from other groups' understandings.

Relevance of Study

The analysis of Title V and any recommendations regarding its future are based in the interpretive analysis of the values, beliefs, and feelings that come from the conversational interviews. More important is acknowledging the opinions, the experience, and the voice of these participants. The purposeful act of silencing minority populations creates oppression and marginalization. One of the principles of social justice is hearing what has been muted or left out of the conversation; policy contributes

to the survival of a society, but it can also enforce social control. In the case of policy making, giving voice to the people affected by legislation on the ground, along the front-lines of the day-to-day work, is a way for policy makers to receive feedback. Or in the case of this study, sharing the meanings of my participants connects the lived experience of Indian and non-Indian alike working in or for the delivery of urban Indian healthcare. Perhaps this is critical to the success of the organizations and the future of Title V. I believe giving voice to Title V stakeholders is an important first step in understanding the effects and ramifications of this policy, because it has not been sought after.

This descriptive-exploratory study is unique in that it focuses on the experience of Title V stakeholders, namely the executive leadership of UIHOs. This study employs qualitative methodologies to identify how UIHOs administering the federal provision of health care access to urban American Indians understand Title V and interpret its meaning in order to provide that care. There is a lack of service delivery information about this group, similar to the lack of health data on American Indians living in urban communities. I pose the following question: nearly 36 years after its passage, what is the interpretation of Title V by those providing health care access to urban Indians today?

Methods

To understand the focus of my inquiry into the meaning of Title V, I conducted an interpretive policy analysis: document analysis, observation, and interviews. These three steps represent the essential interpretive methods for identifying communities of meaning and their symbolic artifacts, thereby establishing a deeper understanding of my topic. The term *communities* or *community* is used as a reference to people who share an interpretation of, or implementation of, a policy, and not the shared geographic location

of the term *community* (Yanow, 2000). In this study, the participants form a community of meaning based on their shared roles or experience as executive leadership in UIHOs.

Document Analysis

I began with analysis of the historic documents outlining the purpose and creation of federal Indian health policies, with most of my focus given to the Indian Health Care Improvement Act and Title V (IHCIA, 1976). I supplemented my understanding of the intent of the IHCIA with a review of the legislative history leading to the passage of the Act through Congressional hearings, testimonies, and supplemental reports found in the Congressional Record volumes 121-122 (1975; 1976) at the Library of Congress. I followed this with a review of the congressional reports and ensuing tribal health reports by the Indian Health Service (IHS), National Council of Urban Indian Health (NCUIH), National Indian Health Board (NIHB), National Congress of American Indians (NCAI), and various media outlets regarding the failed reauthorization of the IHCIA between 1992 and 2009.

With the passage of the Patient Protections and Affordable Care Act (P.L. 111-148, March 23, 2010), now referred to as the Affordable Care Act or ACA, came permanent authorization of IHCIA under Title X, so I reviewed the historic record by Congress and various tribal health agencies. My document analysis yielded hundreds of articles and reports; I limited my review to the final legislation reports and supplemented my understanding of current legislative history with publications from IHS, NCUIH, NIHB, and NCAI. I also utilized articles found through literature searches in PsychInfo, PubMed, Web of Science, and other social work and public health databases at the University of Utah. My search terms began with the Indian Health Care Improvement

Act; because of the variations in which American Indians are defined, labeled, or referenced, and the lack of research on this topic, I used a combination of Boolean operators (*and, or,* and *not*) and truncation to retrieve health policy topics for urban Indian, urban American Indian, Native American, indigenous, off-reservation, and tribal. This process yielded the context to begin interviews because I was creating descriptions of legislation, historical context, and gathering how others in the literature spoke about the IHCIA and, where possible, urban Indian health care.

Observation

Over the course of 3 years (2009-2011), I attended national meetings on urban Indian health policy issues (specifically), as well as state and national health services research conferences that provided sessions on the creation, implementation, or policy implication of the Affordable Care Act. Through participant observation, I noted the spoken language used to describe current policy or service delivery issues within urban Indian health or the Indian Health Service and Department of Health and Human Services, as well as observed the interactions and characteristics of meeting attendees or presenters. I organized my hand-written notes taken during meetings with any comments, thoughts, or additional questions I made after reviewing the notes. When possible, I asked for clarification and meaning from speakers during these meetings. I found this process most beneficial to the creation of my research question, as well as to identify stakeholders as potential participants.

Interviews

Interviews are well-suited for this type of inquiry because the study is exploratory. No other study has spent time determining the perceptions of these stakeholders and how it is related to meaning. Interviews were scheduled for a minimum 1-hour period to accommodate schedules of my participants. The document analysis not only aided in the creation of my research questions but also the interview guide. As part of my qualitative inquiry, the information I discovered in the documents could be checked during interviews or supplement my conversations with participants. Three major questions were addressed in the interviews:

1. What is the role of Title V?
2. How did you learn about Title V?
3. How do you define Title V?

Based on my research question, I created an interview guide to elicit demographic information about the stakeholder's UIHO and their responsibility and Title V knowledge. Questions about the stakeholder's agency focused on the history and client demographics. Funding questions focused on the types of financial support used to maintain operations, percent of operating budgets reliant on federal contracts and grants, and thoughts on the elimination threats to Title V federal funding. Title V questions were related to the ways in which the participant became familiar with the policy, and their overall experience with the policy.

Because my participants were located across the nation and acknowledging the importance of their leadership position, telephone interviews were the best option due to time and resources. Using a SONY ICD-PX820 recorder with an OLYMPUS telephone pickup microphone, I recorded each phone interview (averaging 1½ hours in length) and

reviewed raw data prior to transcription. Transcription was done by a local, professional transcription service and in keeping with the nature of the participant's answers responses, were transcribed in the form of narratives.

Participants

To understand the consequences of a policy for the broad range of people it was intended, I required local knowledge of the everyday and the expert understandings of practical experience with Title V. There is a difficulty and limitation in sampling urban Indians because the population that actively seeks care or is connected to its community is never comprehensive of the total or estimated census population. For this original research, I overcame this limitation by focusing my attention on the policy-driven levels of urban Indian health care. The participant selection process for the interviews was purposeful and specific to Title V stakeholders identified by their leadership position in an UIHO. The most current and comprehensive contact information for UIHOs was available through resource directories provided by the National Council of Urban Indian Health, the Indian Health Service, and the Urban Indian Health Institute websites.

An electronic letter of invitation to participate was sent at two distinct times in 2011; many participants gave me suggestions or contact information for potential interviews based on this inquiry. Participants were assured of their confidentiality and that no identifying information would be tied to their responses. The confidential participation of all interviewees was held in accordance to the NASW Code of Ethics. Interviews were conducted with 15 executive directors at UIHOs across the United States in order to reach saturation. This number of participants' represented all types of existing UIHO programs (levels of care) and the geographic diversity of the UIHO; 8 women and

7 men participated in the study, and all but two self-identified as either American Indian or tribal affiliation (Table 3.1).

Data Analysis

I used interpretative policy analysis (IPA) as a framework to look at my data from review of the policy artifacts and formulation of the communities of meaning (UIHO leadership). IPA identified themes of meaning from the interviews because it gave me the framework to pull-out the participants expressed understanding of Title V. From the stakeholder interviews, I clarified the types of meanings given Title V, and how these professionals demonstrate their understanding of the policy through shared communities of language, definitions, or the way in which health care services are provided.

I began with data reduction to organize and prepare the raw data, which included transcription of the audiotapes, typing my interview/field notes, and sorting the data by type (interview) or source (field notes). Analysis of transcripts occurred in several stages, starting with data immersion. This step provided a general sense of the overall tone and context of the interviews and allowed me to check the transcripts for mistakes. Next, after an initial reading of the transcripts I revisited the transcribed data to become familiar with what I was seeing and to record my overall impressions and ideas about the interviews. During this analysis of the transcriptions, I began utilizing IPA to identify emerging themes/interpretive communities. As Yanow states, " Interpretive communities arise around a shared point of view relative to a policy issue… some common points of beginning reference are those factors according to which a society or polity categorizes itself: race-ethnicity, class, age, religion, political ideology, professional or occupational experience…." (2000, p. 37). Coding line-by-line created my topics through

identification of descriptive words similar to language from the literature and Title V policy; this step of IPA identifies the communities' "discourses": how they talk and act with respect to Title V (Yanow, 2000, p. 20). I coded the communities of meaning/themes using a different color to represent independent themes. Multiple themes were either merged or separated as appropriate. This analysis generated descriptors of interview responses and themes that included detail towards Title V-specific references and language (Creswell, 2009, pp.185-190). Using Yanow's framework (2000), the last step in the analysis was the descriptive analysis and interpretation of meaning from the thematic artifacts identified during data coding (Figure 3.2).

Themes

From the interviews conducted with stakeholders, I clarified the types of meanings given Title V, and how these professionals demonstrate their understanding of the policy through shared communities of language, definitions, or the way in which health care services are provided. This section examines how this IPA framework is important because these understandings are most likely the driving force, whether explicit or implicit, behind actions these stakeholders make in the delivery of health care services, decisions made for the level of care provided at a UIHO, and determining the types of services they can or will provide in their Urban Indian Health Organization. In order to maintain confidentiality and reduce the reader's ability to identify the speaker based on their gender, race, or location, I distinguish the speaker of each quote by using a characteristic.

Role of Title V

Two roles of Title V emerged from these interviews: a) funding and the provision of services, and b) unmet need. The function of Title V was regarded as the funding mechanism that enables the programs to be known as an UIHO, and in doing so provide services to federally recognized Indians through direct receipt of Title V contracts and all associated grants. However, it is also the mechanism that allows other federal monies to be sought or obtained because the UIHOs are able to show federal contract experience, thereby leverage Title V funding to receive other funding for more services. They reported unmet health care needs due to lack of adequate Title V funding, so many UIHO must seek other sources of funding; a unique issue was brought up regarding the limitations by Title V funding provisions to ONLY federally recognized tribal members. By utilizing non-Title V or non-IHS health funding. It allows provision of services to all American Indian/Alaska Native clients in their agency regardless of federal status.

Funding and Services

Each stakeholder acknowledged that their Title V funding was used to provide access and services for the intended population (urban Indians).

Participant 13 (female): "Title V is more than legislation. It's how we get our money in order to do those activities that are listed in our contract."

Participant 10 (female): "This funding, what it did for us was it provided a much more comprehensive package of services for our Indians. …with Title V, we turned away anyone who wasn't Indian. I mean, we couldn't see anyone else, and (early on) we really weren't looking to provide non-Indians. I mean, we were just there to provide services to Indians."

Participant 15 (female) "... we're providing the access, but we're only doing it because we have the money and the only stream of money is through Title V."

If Title V monies were eliminated or reduced, the extra services currently provided only to urban Indians would be eliminated or reduced, and for some UIHOs their entire agency would be affected.

Participant 4 (male): "Because we get these (Title V) federal grants, we just draw down money when we need it, so we don't need to have a cash reserve equal to two-month reserve. I guess it we lost a federal grant like Title V, we'd just close anyway."

Participant 10 (female): "We wouldn't close our doors without Title V funding, but we wouldn't be able to provide Indian-specific services. For example, we're able to provide Indians much better services, a bigger package of care. Our diabetes dollars allow us to provide eyeglasses and shoes and the more comprehensive diabetes care with a dietician and specialists and optometry. All of those services we're able to provide more of to Indians. The rest of our population, they don't get the eyeglasses, they don't get the shoes. If those dollars were taken away, then they wouldn't get any of that stuff either because a great deal of that is funded by Indian health service."

Unmet Needs

The majority of stakeholders spoke about the influence Title V funding has in receiving other federal and state contracts or grants (ability to leverage); they seek these opportunities to provide health care that otherwise goes unmet by Title V alone. In the UIHO system, 15 programs are established FQHCs and provide care to a Native and non-Native client base. It is how they survive fiscally. However, they believe that if Title V funding were eliminated or reduced, they would continue providing care to urban Indian communities and still remain connected to the cultural aspect of care and their identity/history/origins. Some UIHOs began operating as FQHCs through Title V designation in the 80s and 90s, while others began as federally funded 330 Community Health Centers either prior to creation of the IHCIA or decision by the urban center's governing boards to apply for 330 status regardless of IHCIA. Funding known as 330

refers to Section 330 of the Public Health Service Act and are grant monies designated for health centers to provide care to underserved, and often uninsured, populations.

Participant 5 (male): "I've heard that Title V funding under IHS is around 1%. So 1% of the resources of the agency are devoted to serving the population that's about 60-70% of the Indian population. That's, you know, that's disproportionate… if anything, we want to see more resources for the tribal communities, but we also recognize that it's just ridiculous to think you're going to meet the needs of 70% of the population with 1% of the budget."

Participant 12 (female): "Having designation as a community health center and Title V are both very much an important component. What it allows is for us to be able to effectively cover the encounters that we already are doing for people that are Native."

Participant 10 (female): "The specific policy for Urban Indians leverages our position to get started and to stay open. I mean, that's what all federal money is about. I don't like the idea of seed money because it goes away. But the feds, I think they got something right when they say we'll give you money but we expect you to go out and get more. But the Title V program, they never really said that and I don't think they were really expecting that and a lot of people were just saying, okay, I've got this money and I'm going to spend it. They weren't thinking about leveraging…it's a different approach and I think IHS is starting to see that that should be the approach for Title V too."

Participant 11 (female): "In our city… Natives who by all accounts in terms of community (are Native), but may not necessarily have the documentation that meets IHS requirements, so we applied for 330 funding to be able to help cover that shortfall. But also because we know to really continue and to be viable that the more that you are able to provide services to, the most cost effective you can be as an organization. If we were only dependent on Title V funding, which we are right now, it would have devastating effects on our agency to continue."

Participant 14 (female): "All the other funds have increased the complexity of care and the comprehensiveness. …The reason we can provide all of those services isn't because of that 4-in-1 money (a federal grant attached to Title V contract) that came much later, but it's because we could access (other) healthcare money."

A few participants made reference about President George W. Bush's February 2006 announcement to eliminate funding to the Urban Indian Health Program (see Chapter 2 for a description about this event). Shortly after, UIHOs were invited to a meeting held in Denver, Colorado. In attendance were various Indian Health Service

staff and the topic of discussion was about the future of UIHOs if funding was eliminated. The message heard during those Denver meetings prompted a reaction.

Participant 4 (male): "Remember how they called us all to Denver after Bush proposed to close us down? And they had HRSA and the IHS there to tell us how to close down our federal program. They said, 'well, you know there's always 330 money and here's some ladies from HRSA's minority outreach program to tell you all about the 330 program.'"

And finally, nearly all participants spoke about the role their UIHO has in providing care to Indians who qualify for care from either an IHS or tribal health care center located 100 miles or less from the UIHO. While UIHO funding is widely considered insufficient to cover care for urban populations, some UIHOs do not turn away a Native in need of care. Attached to this same notion is the pride UIHOs have in their connection to, and provision of, culturally competent care that is not provided elsewhere.

Participant 9 (female): "We get people from the feds. We have an excellent relationship with the officers of the court and they send people here who have been sentenced to prison… but they don't pay for them, that's why they send them to us. Tribes don't pay either. They (tribes) will send someone here because if they send them to a non-Indian facility, it might cost $5,000.00 to $10,000.00 which they would have to pay."

Participant 8 (female): "The clients who live in our area, it isn't that they have nobody else (for care), there are other agencies. But they're resistant to care from them because Indians are different from other people. If they go into an agency, like a welfare type agency, and they're insulted, they don't go back."

Participant 10 (female): "(The founders of our program) were known in the community for their philosophy that Indian people should take care of all people."

How Did You Learn About Title V?

Most executive directors/leadership received their Title V education from other UIHO executive directors, program managers, and rarely from Project Officers or Contract Offices in IHS. A large number of participants' mentioned Martin Waukazoo, Bay Area UIHO director, and Ralph Forquera, Seattle UIHO director, as their source for

Title V information—by personal correspondence or conference attendance; together, these men have a combined 70 years experience in urban Indian health care delivery. Both were referenced as inspirations and use their agencies (both men oversee FQHCs) as models for the participants' own agency system design, and both men were considered trustworthy and knowledgeable advocates of Title V. Just a note, both men gave me permission to use their names for this article.

Participant 11 (female): "I was introduced to Title V really early on…oh my gosh, like two weeks after I was on the job I had a meeting scheduled with UIHI in Seattle (Ralph Forquera's agency). …and then I attended the NCUIH conference so that was a real early introduction."

Participant 12 (female): "Was an Indian Health Care Improvement Act 101 class taught by (their IHS area office)? What are you thinking? That's hilarious! No, it was completely self-taught. But I reached out to those mentors who were intimately familiar with the law, like Ralph and Marty."

Participants 8, 9, 11, and 12, all made similar statements that as soon as they began work as a UIHO director, they were forced to understand Title V quickly because IHS was threatening to take contracts away from their agencies.

Participant 12 (female): "I mean, my first day there (at work) when I talked to our urban (IHS) coordinator, that's what they were talking about and I immediately had to understand and learn more about it… because I was trying to figure out how to keep the resources for my center."

Participant 9 (female): "Within a week of my start, I just came in and there's a site review and I had just spent the previous week writing policies and procedures. I was at a great disadvantage because I didn't even know the concept of IHS. …the area office met with my board and they met with me. They said this was our last chance."

Many participants spoke to the political nature of their role in their agency, making it clear that the role of an urban Indian director requires them to understand the political structure in which they exist to be able to provide what's best or needed for the community they represent, how to provide service, or manage their agency.

Participant 13 (female): "I think that there could have been a better communication to people in general who don't find themselves necessarily interested in the policy, but since this is my job, it's my responsibility to know what the heck is going on."

Definition of Title V

"Symbols serve to unite those who share their meanings while setting them apart from other people or groups who do not" (Yanow, 2000, p. 14).

Overall, executive leadership at an UIHO believe it is critical to understand the policy on their own terms and not allow for interpretation by those not affiliated with the provision of services in an UIHO.

Participant 5 (male): "So, under Title V, which is under the Indian Health Care Improvement Act, funding was established for providing services to American Indians living in identified urban centers throughout the United States. As a result of that funding, there are currently 32 clinics throughout the United States."

Participant 10 (female): "Well, I define Title V as the overall policy to ensure that American Indians and Alaska Natives get health and education, that we're part of the treaty agreements with the U.S. So it's to help ensure that those still go forward. And then, the Title V part was brought in as part because natives were relocating to the urban areas, so they're not a part of the reservation system or tribal government system. So, they were brought in to help ensure that we had access to funding as well."

Participant 4 (male): "I would define it as the Indian Health Service money designated for the provision of care to urban Indians. The Title V program, what it means to this organization or me, I guess, is our ability to see Native Americans for whatever services that we provide without any kind of qualifying criteria other than they have to be Native Americans. Regardless of income, regardless of anything else, any other factor, that they're Native American."

Participant 11 (female): "Title V is a unique privilege that really allows Indian health care to embrace all tribal members whether they're on the reservation or off the reservation. And that number has grown significantly over the years, so it's a way for the government to basically maintain its trust responsibility to tribes and provide health care for tribal members. Whether that was the original intention or not, I don't know, but that's really how I see it. And that's what I will emphasize or expand upon if ever I'm discussing what it is that we do with tribal members or tribal health directors is to make that connection. Because I think historically there was a propensity for there to be a view of Title V programs by some tribes as something that takes away from tribes. And I think that was really sort of developed out of just a lack of resources overall."

Participant 13 (female): "I think that the regulations are a starting place and if you accept the regulations as they are written, then you're part of the problem."

Participant 15 (female): "I think our strength within the delivery system is growing and I think you have to have an understanding of Title V in order to actively participate with the Indian Health Service system, and tribal leaders, in order to benefit your UIHO that has a Title V contract."

Issue of Permanency in the ACA

Collection of data for this study occurred after the IHCIA was given permanent authorization within the ACA. Many participants told how they learned about Title V's permanency, as well as how the ACA overall would, or has, impacted their health centers. Some participants were in the process of updating or changing their health records management data systems in anticipation of their position in the ACA infrastructure. Others talked about how it was still too new to understand how the ACA would be implemented in the UIHO system; but they felt the political nature of the ACA warranted increased education about the role of UIHOs and their unique contribution to any health care delivery system.

Participant 13 (female): "I was following the legislation. I'm a policy wonk. I love policy… so I knew what was going on. I was definitely part of it (the inclusion of IHCIA in the ACA)… there were a lot of things that were pending and we were just waiting for reauthorization and when it happened, I mean, I was thrilled."

Participant 4 (male): "I think in terms of the future of Indian funding, I think as long as we have a friendly administration, I think we can grow. And I think this is the opportune time to dig in our heels and make ourselves more known and make our services more key in providing services to our (entire) population in the cities we serve."

Participant 10 (female): "You know, what I've learned in the last few weeks is the importance of divorcing ourselves from the Obama care talk, because we are not Obama care. We were around long before that and that's what everybody is afraid of. That is what the tea party is afraid of, and what everybody hates is Obama care. So when I went on the Hill, I had to convince everybody that we were not. We've been around for 35 years…. They thought we were Obama care and they're all CEOs of small businesses. So I thought our message needs to be not about us as an UIHO that is suffering and needs the government to help us, but that we are a cost-effective UIHO providing good

care and we have a history of 35 years. I mean it makes you realize that you need to change your approach to get the same thing- money."

Conclusion

The purpose of this qualitative, exploratory inquiry was to understand Title V from the perspective of UIHO stakeholders and give voice to the urban Indian health population that is rarely researched for their experience, and discover how a federal policy intended to improve access to health care is understood. Both of these components contribute to an understanding of Title V that has never been explored since the inception of the policy. I revealed UIHO executive leadership as a distinct Title V community of meaning. Every participant of this study shared similar understandings, definitions, and historic context to Title V based on their administrative roles at the UIHO and with each other (providing education and training to new executive directors, conducting meetings and conferences specific to the provision of Title V services, and creation of an informal support network among UIHO directors and agencies). Within the UIHOs, this linkage promotes the individual UIHP community-driven health outcomes and the types and provision of services to address the intended outcomes.

This study revealed that UIHO leadership is its own community of meaning, and their group identification as a *community* reveals shared understandings of the Title V policy ideas and language. Policy-relevant groups interpret a wide range of acts, from agenda setting acts to acts of legislating and implementation; this is known as communicating policy meanings. The actions of an agency related to their interpretation of a policy may be understood by members of the public to communicate policy meanings (Yanow, 2000).

Every participant referred to their agencies as part of a larger system of care that provides access, and that this role is an essential part of the U.S. government's obligation to provide health care to American Indians regardless of where they live. Whether an agency was established prior to or after the passage of the IHCIA, these UIHOs pride themselves for providing services in culturally relevant ways and keeping strong connections to their "nativeness."

Compared to other medical or health resources available in their urban area, UIHO directors view their agencies as a unique, viable service to urban Indians and non-Indians; and when a tribal or IHS health center is in close proximity to an UIHO, most saw themselves as an alternative to either IHS or the tribal facility and that the UIHO will see all Natives who qualify or have need. The UIHOs these study participants are affiliated with have all sought additional health care funding opportunities in order to provide care that Title V funding alone cannot meet. With changes coming from the ACA (discussed further in my next article), the participants of this study see an expanded UIHO role in their communities.

UIHO leadership uses Title V to create unique spaces for care and for community; these centers represent: a place of belonging for its urban Indian population, whether or not they can show citizenship in a federally recognized tribe; something different from experiences with an IHS or tribal clinic; and understand that their UIHO is often the only health care option for urban Indians. The rich, historic context of the creation of UIHOs-- many urban programs did not exist prior to Title V while others communities that had urban centers/hubs (Lobo & Peters, 2001; Ramirez, 2007; The Harvard Project, 2008) applied for Title V status and subsequent monies-- challenges the representation of urban

Indians as separated from Indian culture or identity. UIHO executive leadership work within the context of Title V's original intent and to an extent have embraced the importance of Title V. However, what has been created was done in the image of the community they serve, not the people who appropriate money to them through Title V. The success of the UIHOs, according to those who participated in this study, has come to those who have not forgotten where they come from, to those who connect to the mentors and advocates who don't forget why Title V was created, and to those who continue to provide services to American Indians regardless of where their clients come from.

Limitation of the Study

This was an exploration of those whose understanding of the policy is central to the administration of the federally funded urban Indian health care delivery system; I did not interview clients/consumers of UIHO services. While executive leadership at UIHOs value the delivery of services/the output of the Title V implementing organization, this is not the only act in which the clients of those services may find meaning (Yanow, 2000). Perhaps clients/consumers interpret the purpose of UIHOs as extensions of the IHS system of care. Further study would need to look at the consumer side of UIHO as its own interpretive community, for which they too will possess different localized knowledge of the nature of their relationship to Title V. Further studies may determine how this community of meaning is different from other groups' understandings.

Summary

Urban Indian Health Organizations, through Title V of the IHCIA, were created to identify the gaps between unmet health needs of the urban Indian population and the resources available to meet such needs. They have done this by utilizing other federal

programs like Community Health Centers. Though President Obama has proposed increases to address funding gaps in the IHS, funding still remains flat for the UIHP (NCUIH, 2012). A flat budget is actually a cut for existing programs.

The failure of Congress to pass timely appropriations bills over the past 2 years has prevented Urban Indian Health Programs from obtaining desperately needed increases in funding (NCUIH, 2012). Due to the chronic underfunding of the Indian Health Service, the Urban Indian Health Program is also desperately underfunded (Table 3.1). The success of an UIHO is directly related to the existence of the policy because it authorizes the federal obligation to provide health care to citizens of federally recognized American Indians regardless of their place of residency (the difference of living on reservation from off-reservation), or the ability of the UIHO to leverage its Title V designation to seek funding to provide care that a) is not covered by Title V funding alone, or b) provide care to all AI/AN based on ancestry regardless of federal recognition. This study can be used to develop further research to understand relationship to the function of service delivery, health outcomes, and the policy with other as-yet identified communities of meaning.

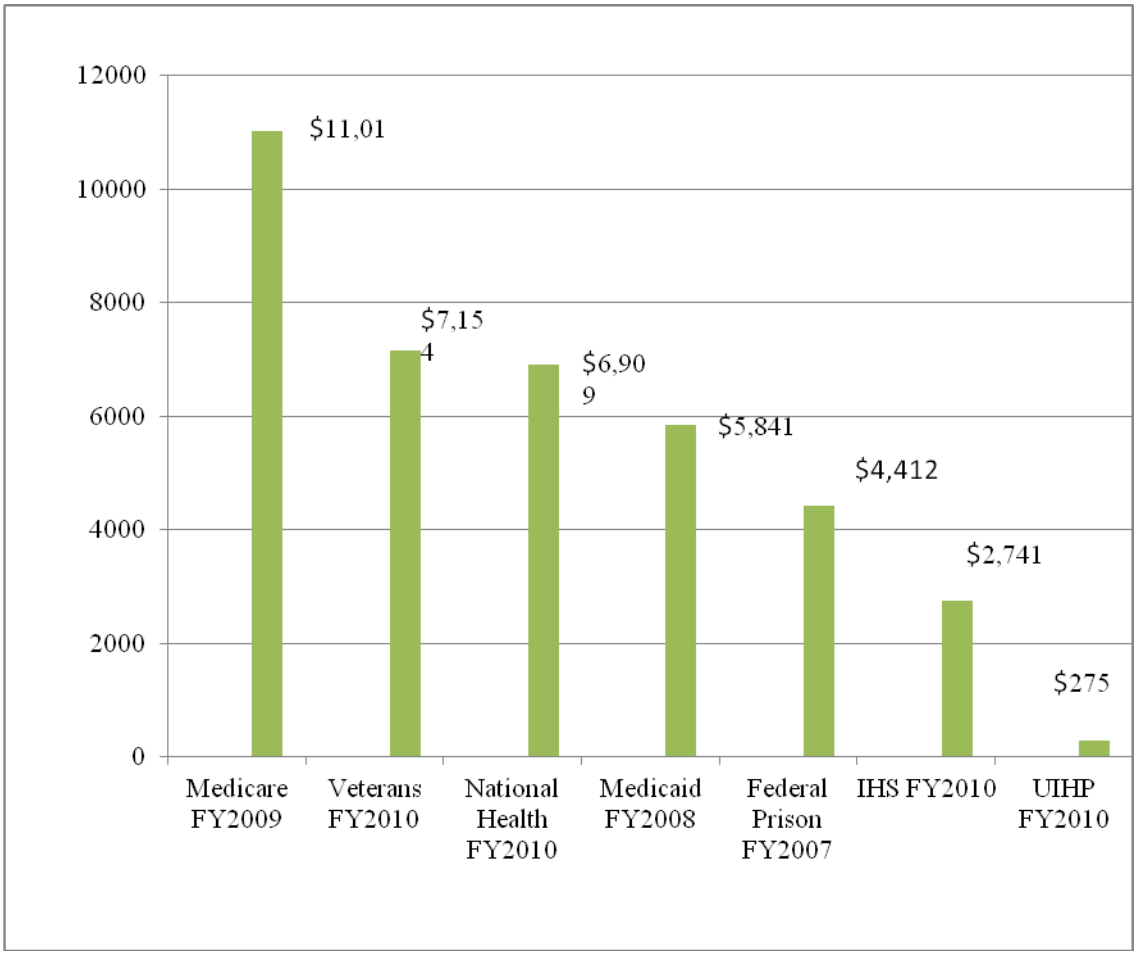

Figure 3.1: IHS Expenditures Per Capita and Federal Health Care Expenditures Per Capita Sources (Sources: National Congress of American Indians, 2012; U.S. Department of Health and Human Services, 2012; U.S. Department of Justice, 2008)

STEP I:
Identify language, objects, acts (artifacts) that are significant carriers of meaning for Title V/policy issue, as perceived by policy-relevant actors and interpretive communities
STEP II:
Identify communities of meaning/interpretation/speech/practice that are relevant to the policy issue under analysis
STEP III:
Identify the discourses: the specific meanings being communicated through specific artifacts and their entailments (in thought, speech, and act)

Figure 3.2: Communities of Meaning Process (Source: Yanow, 2000, p. 22)

Table 3.1: Characteristics of Participant Stakeholders

Participant	Gender	Identity+	Years in position++	Geographic location*
1	M	AI	>10	Billings
2	M	AI	>30	Portland
3	M	AI	>30	California
4	M	AI	>10	Phoenix
5	M	AI	>10	Nashville
6	M	AI	>10	California
7	M	AI	>30	Phoenix
8	F	N-AI	>10	Nashville
9	F	N-AI	>20	Aberdeen
10	F	AI	>10	Oklahoma City
11	F	AI	<10	Bemidji
12	F	AI	<10	Portland
13	F	AI	<10	California
14	F	AI	>10	California
15	F	AI	> 10	California

+ AI= American Indian; N-AI= non-American Indian/Other
++ Approximation of years in their agency OR years working in urban Indian organizations; to protect confidentiality I have selected years in 10-year increments vs. actual years
* Based on 12 IHS service areas

References

Brayboy, B.M.J. (2005). Toward a tribal critical race theory in education. *The Urban Review*, *37*(5), 425-446.

Congressional Record Vol. 121 (1975)

Congressional Record Vol. 122 (1976)

Indian Health Care Improvement Act of 1976, Pub. L. No. 94-437, § 501 et seq. 90 Stat. 1400 (1976).

Indian Health Service. (2012.) Indian health service FY 2010 budget. Retrieved March 20, 2012 from http://www.ihs.gov/PublicAffairs/IHSBrochure/Budget10.asp

Indian Health Service. (2012). Urban Indian Health Programs. Retrieved March 20, 2012, from http://www.ihs.gov/NonMedicalPrograms/Urban/UIHP.asp

Karger, H.J., and Stoesz, D. (2010). American Social Welfare Policy (6th ed.). Boston: Allyn & Bacon.

Lobo, S., & Peters, S. (Eds.) (2001). *American Indians and the urban experience*. Walnut Creek: Alta Mira Press.

National Council of Urban Indian Health. (2012). *IHS FY2014 Area Budget Formulation National Council of Urban Indian Health Budget Request on The Urban Indian Health Program Line Item*. Washington DC: National Council of Urban Indian Health.

Northwest Portland Area Indian Health Board. (2010). *The FY 2011 Indian Health Service Budget: Analysis and Recommendations. 21st annual report* given March 12, 2010.

Ramirez, R.K. (2007). *Native hubs: Culture, community, and belonging in Silicon Valley and beyond.* Durham: Duke University Press.

The Harvard Project on American Indian Economic Development. (2008). *The state of the native nations: Considerations under U.S. policies of self-determination.* New York: Oxford Press: Author.

Urban Indian Health Institute. (2012). About urban Indian health organizations. Retrieved March 22, 2012, from http://www.uihi.org/about-urban-indian-health-organizations/

U.S. Census Bureau. (2012, January). *The American Indian and Alaska Native*

Population: 2010 census brief. Retrieved March 22, 2012, from http://www.census.gov/prod/cen2010/briefs/c2010br-10.pdf

U.S. Department of Justice. (2008) Federal Bureau of Prison's Efforts to Manage inmate Health Care. Retrieved March 22, 2012, from http://www.justice.gov/oig/reports/BOP/a0808/final.pdf

U.S. Department of Health and Human Services (2012). National tribal budget recommendations for the Indian Health Service fiscal year 2013 budget. Retrieved March 22, 2012, from http://www.nihb.org/docs/03282011/FY%202013%20National%20Tribal%20Budget%20Recommendations_Final.pdf

Yanow, D. (2000). *Conducting interpretive policy analysis*. (Sage University Papers Series on Qualitative Research Methods, Vol. 47). Thousand Oaks, CA: Sage.

CHAPTER 4

ARE HEALTH POLICIES FOR URBAN AMERICAN INDIANS SOCIALLY JUST?

Introduction

The original purpose of federal Indian policy was to assimilate or eradicate the indigenous inhabitants of the U.S. and dislocate them from their land and their socioeconomic, political, religious, and cultural existence. As each attempt by the U.S. government failed to reach its goal to address the "Indian problem," new policies replaced failed policies and moved towards an era of government support for self-determination and acknowledgment of the trust obligation—specifically for the provisions of health and welfare. A critical examination of whether Title V renders the type of support necessary to raise the health status in urban Indian communities is offered. The overarching question is how have physical and mental health care, including health promotion and disease prevention activities, been created in the unique voice of urban Indians, whereby their collective voice is included in the authorization of health policy? Leaving their voice out of the policy-making process would be socially unjust and an extension of a legacy of federal policy imposed on a historically marginalized population.

A Global Social Justice Issue

The United Nations Declaration on the Rights of Indigenous Peoples was adopted in June 2006, after more than two decades of effort to maintain, protect, and strengthen the rights of indigenous peoples worldwide. The early language of the declaration was a concern to a number of States with regard to some core provisions on self-determination and the control over natural resources that existed on indigenous peoples' traditional lands (United Nations Permanent Forum on Indigenous Issues, 2012). The first international decade of the world's indigenous peoples was 1995-2004; established in 2000, the United Nations Permanent Forum on Indigenous Issues (UNPFII) has set five objectives for the second decade of concentrated action through 2015:

1. Promoting nondiscrimination and inclusion of indigenous peoples in the design, implementation, and evaluation of international, regional, and national processes regarding laws, policies, resources, programmes, and projects;
2. Promoting full and effective participation of indigenous peoples in decisions which directly or indirectly affect their life styles, traditional lands and territories, their cultural integrity as indigenous peoples with collective rights, or any other aspect of their lives, considering the principle of free, prior, and informed consent;
3. Redefining development policies that depart from a vision of equity and that are culturally appropriate, including respect for cultural and linguistic diversity of indigenous peoples;
4. Adopting targeted policies, programmes, projects, and budgets for the development of indigenous peoples, including concrete benchmarks, and particular emphasis on indigenous women, children, and youth;
5. Developing strong monitoring mechanisms and enhancing accountability at the international, regional, and particularly the national level, regarding the implementation of legal, policy, and operational frameworks for the protection of indigenous peoples and the improvement of their lives.

The purpose of the UNPFII is to strengthen international cooperation for the solution of shared global issues/problems faced by indigenous peoples. It is important to understand the work happening internationally because the social issues of American

Indians/Alaska Natives (AI/AN), like history of colonization, economic status, health inequalities, loss of land, are nearly identical in relation to Indigenous, Aboriginal, and First Nations Peoples globally. Deep-rooted oppression and colonization by state (in the federal or national sense of the word) government of its native peoples is found in that state's policies to bring its citizens to a selected "norm" through assimilation. I see the importance of countries that were created by conquest or annihilation of its original inhabitants to agree to, adopt, or enforce the articles of Declaration on the Rights of Indigenous Peoples. In so doing, these countries acknowledge past abuses and injustices, and recognize indigenous human rights. That said, when the Declaration was placed for a vote in September 2007, the general assembly voted 143 in favor and 4 against: Australia, Canada, New Zealand, and the United States (Stephens, Porter, Nettleton, & Willis, 2007). Since then Canada, New Zealand, and Australia have all adopted the Declaration. The U.S. became the last nation to drop its opposition and gave its support for the Declaration in December 2010--President Obama announced he would reverse the Bush administration's position made at the time of the 2007 signing. The President stated, "But I want to be clear. What matters far more than words, what matters far more than any resolution or declaration, are actions to match those words" (Richardson, 2010). The UN ambassador during the George W. Bush presidency was John Bolton. Upon hearing Obama's announcement, Bolton stated it was "exactly the kind of mushy, feel-good multilateralist gesture one would expect from President Obama" (Richardson, 2010).

The U.S. as an independent country is relatively young compared to other global, independent countries. Many of today's Westernized countries have legacies of colonization, just like the U.S. health inequalities of the world's Indigenous peoples are

widespread in countries founded by colonization. So how is the U.S. addressing the health inequalities found in the American Indian population, its Indigenous peoples? This article identifies emerging issues and recommendations regarding Title V of the Indian Health Care Improvement Act. Using TribalCrit as the theoretical framework (Brayboy, 2005), I explore how the voices of urban Indians are organized to be heard or represented in the federal health policies for American Indians. TribalCrit addresses the concepts of culture, knowledge, and power created through a Western or colonized perspective, and offers alternative ways of understanding through an indigenous lens the liminal space created by urban Indians (Brayboy, 2005). This is important because no one has asked why the health inequalities found in urban Indian communities still exist after the passage of a federal policy 35 years ago that intended to provide the highest possible health status to all AI/AN regardless of their location.

Social Determinants of Health

Urban American Indians experience significant health and behavioral health inequalities compared with the general U.S. population. Globally, there are similar health disparities of indigenous peoples that can be linked to colonization and urbanization (Gracey & King, 2009). By utilizing social determinants of health framework for analysis, these health inequities can be seen as largely the result of historical, social, and behavioral determinants, as well as the varied political and legal responses by foreign governments and the United Nations as compared to the U.S. history of Indian federal policy.

The term *social determinants of health* (SDOH) derived from 20th century studies to identify the ways in which members of differing socioeconomic groups experience

varying degrees of health and illness (Raphael, 2006). This perspective shifted focus beyond individual health factors and the individual interventions to address those health issues, to looking at factors in the environment/the social context in which they occur that may contribute to group differences. Differences in health measured by inequalities in economic, social, racial, or ethnic status have been observed globally, and these determinants account for a variety of health outcomes such as prevalence of heart disease, diabetes, mental illness, stress, and suicide (Marmot & Wilkinson, 2000). To understand the impact of SDOH provides a better understanding of how society operates (Marmot, 2000).

The World Health Organization (WHO) presents that social justice is a matter of life and death. In 2005 and in the spirit of social justice, WHO established the Commission on Social Determinants of Health to advance a global approach towards understanding the factors that shape health equality. They define SDOH as the conditions in which people are born, grow, live, work, and age, including the health system. These circumstances are shaped by the distribution of money, power, and resources at global, national, and local levels, which are influenced by policy choices. The SDOH are mostly responsible for health inequalities -- the unfair and avoidable differences in health status seen between and within countries (Commission of Social Determinants of Health, 2008; Marmot, 2005). Social factors are powerful influences on health, and their impact on health means the difference between well-being and full participation in society (Braveman, Egerter, & Mockenhaupt, 2011).

To comprehend the health status of urban American Indian communities, the relationship between the underlying determinants of their health inequalities must be

made to the root causes of the U.S. government's legislative actions. Whereas the Commission on Social Determinants of Health focuses on the *cause of the causes* (for example, the *cause* of diabetes II is linked to insufficient food choice, which is *caused* by low-income or poverty), with the SDOH of Native or Indigenous peoples', there is a shared, third level of cause. In social epidemiology, when you discuss specific disease, there is a discussion about its origins. For discussions on American Indian health, we can and must talk about the source of the problem -- colonization (Figure 4.1).

The history of American Indians is inherently linked to the relationships between the colonizer and the policies enacted to deal with what was often perceived as the "Indian problem." I contend that the health of contemporary American Indians is linked to this past and with the history of federal U.S. Indian policies that promoted assimilation or decimation of American Indian peoples. The goal of these policies were to cut Native Americans from their culture that was intrinsically tied to where they were born, raised and taught their families, sought health and wellness, accessed nutritional and spiritual resources, and buried their dead, essentially leaving what was assumed by the U.S. government as no option but assimilation. These two altering forces, colonization and federal Indian policy, contributed to a cultural and social existence with, "… a lack of economic opportunity, scarcity of nutritious food, environmental degradation, stress resulting from racial stratification, historical trauma, and cultural loss, and other inequities" (Chinitz & Christian, 2009, p. 14). U.S. federal Indian policies have had a greater impact on the health and well-being of American Indians "than genetics or other physical causes of disease" (Warne, 2009, p. 8).

Health Status of Urban Indians

Differences in health status between the majority population and American Indian population relate to the social, economic, and historic factors that differentiate the groups. Even with the creation of a health policy (IHCIA) for American Indians, the policy only offers support to the Indian communities to provide some sort of access to care and not the determinants of their health. Reliable health statistics on urban Indians are scarce because this demographic has been insufficiently researched and its community members are often misclassified on vital records as belonging to other races or ethnicities. What we do know about urban Indians' health is enough to warrant immediate action to collect data (Urban Indian Health Commission, 2007; Zuckerman, Haley, Roubideaux, & Lillie-Blanton, 2004).

Urban Indians are a unique racialized and politicized minority population who continue to disproportionately experience health inequalities consistently linked to high levels of poverty (Urban Indian Health Institute, 2008); this recognition of poverty and health disparities was first noted in the Meriam Report (1923). Health disparities identified in current research highlights the prevalence of chronic disease, the structure and use of Indian health care services, and an American Indian- marginalized socioeconomic status (U.S. Commission on Civil Rights, 2003, 2004; Urban Indian Health Institute, 2004, 2008). Studies from the Urban Indian Health Institute have found that urban Indians suffer from significant health inequality compared with the general population. These inequalities include higher rates of tobacco use, infant mortality, later prenatal care, interpersonal violence, attempted suicide, and deaths due to diabetes, accidents, and chronic liver disease.

Other key findings point to differences existing between urban Indians and the rest of the U.S. population in terms of access to health care, risk behaviors, threats to health, and certain health outcomes. For example,

1. Almost 30% of urban AI/AN report not having health insurance, compared with 18% of non-AI/AN
2. Nearly 1/3 of urban AI/AN have a body-mass index greater than 30 (obese), compared with 20% of non-AI/AN
3. 24% of AI/AN living in UIHO service areas experience poverty below 100% of the federal poverty guidelines compared to 13.5% of the general population living in the same areas
4. 30% of AI/AN under the age of 18 experience poverty below 100% of federal poverty guidelines in the same areas

[Urban Indian Health Institute, 2008]

The political nature of SDOH is prevalent in the health status of urban Indian populations. For American Indians, their unique status as a minority group in American society is a result of history and of federal Indian policy; policy that not only recognizes Indian tribes as independent, political entities, but has also varied between regarding tribes as sovereign equals to attempts to eradicate, assimilate, or terminate tribes. Understanding the political history and cultural need behind the creation of urban American Indian spaces is crucial to understand how urban Indians formed a unique voice out of necessity, survival, and identity.

Tribal Critical Race Theory

According to Denzin, Lincoln, and Smith (2008, p. 73), "…CRT (critical race theory) is not limited to the old notions of race. Rather, CRT is a new analytic rubric for considering difference and inequity using multiple methodologies--stories, voice, metaphor, analogy, critical social science, feminism, postmodernism." CRT values experiential knowledge as a way to inform thinking and research. However, criticisms surround the use of CRT when research and analysis centers solely on race (Darder &

Torres, 2004). If race-centered, the research perpetuates the justification of a peoples' assimilation, degradation, or colonization (racism). As augmentation to CRT, Brayboy (2005) defines Tribal Critical Race Theory (TribalCrit) as a framework that provides a way to address the complicated and unique relationships created between American Indians and the United States federal government. While it emerges from CRT, TribalCrit also values narrative and stories as important sources of data. There are nine tenets of TribalCrit (Table 4.1).

The tenets of TribalCrit offer explanations about how urban Indians became a marginalized population and why the policies and services available to urban Indians are limited and lack inclusion of the urban experience. TribalCrit, as my theoretical framework, gives meaning to the social determinants that impact service delivery and access to care in urban Indian communities, thereby helping me to build substantial knowledge regarding the urban Indian health care system in relation to the policy created explicitly for these communities.

We know that urban Indians do not enjoy self-determination as tribal governments do. Self-determination is the principle that people have a right to govern themselves; the concept of self-determination as it pertains to American Indians (legislated by the federal government under the Indian Self-Determination and Education Assistance Act of 1974) allows tribal governments to directly manage and operate federal programs on their reservation with federal funding. While reservation Indians organize decision-making processes within their tribal governments, urban Indian communities are organized around the delivery of various services like a health center (The Harvard Project, 2008, p. 363), and urban Indians have no clear organizing entity created through

federal policy. The liminal space (where political and racialized identities meet) that exists in an urban Indian health community may determine how urban Indians view themselves and how their voice is represented in the health care policy of Title V; these understandings may vary by geographic location, type of health care service agency or tribal affiliation, and in their own way represents how self-determination can or does exist within urban Indian communities.

This study drew upon Brayboy's theory to link the literature to the stakeholder interviews. The definition of Title V and what meaning it has for the various stakeholders is a crucial question I addressed in a previous article, so for this article, I use a TribalCrit framework to understand the emerging themes from interviews in relation to federal Indian history, identity, policies, and hearing the voice of the stakeholders. In my literature reviews, I saw countless studies conducted about American Indians, and the terms *vulnerable* or *disadvantaged* are often used to describe the conditions of the participants, their situations, or their pasts.

For my study, I am using my investigation as a means to promote social justice by looking at the contextual issues and history underlying the conditions of the participants and their situation to understand their past. As Linda Smith notes, the role of an Indigenous researcher is to produce research knowledge that documents social injustice, and creates space for voices kept silent to be "listened to" (Denzin, Lincoln, & Smith, 2008; Smith, 2006). Consistent with indigenous ways of knowing, this study addresses the question, how are UIHOs understood in federal health care policies?

Methods

This descriptive-exploratory study gives voice to UIHO agencies that are rarely researched about their experience, and discovers how a federal policy intended to improve access to health care for urban Indians is understood; both these components contribute to an understanding of Title V that has never been explored since the inception of the policy. Neither has there been research with stakeholders about how the relationship is (perceived) between UIHOs and the federal agencies that invest resources for the provision of health care that is linked to the federal trust obligation. This was not intended as a traditional policy analysis that looks to measure outcomes based on the intent the authors of the IHCIA/Title V had in 1976. Rather, this was an exploration of those whose understanding of the policy is central to the administration of the federally funded urban Indian health care delivery system.

Within qualitative inquiries is a fundamental appreciation for inductive analysis, purposeful sampling, and holistic thinking (Marshall & Rossman, 2006). This exploratory study was informed by a constructivist ontology that values inclusiveness, pluralism, and strives to ensure participant's voices are present in the construction of meaning (Denzin & Lincoln, 2005). Understanding my exploratory inquiry about health through a cultural lens is an essential component to understanding the perspective of my participants, because they have created culturally specific spaces or agencies for the provision of health care; that same perspective is also critical for creating socially just health policies for urban Indians. Through in-depth interviewing with Title V stakeholders, I noted two themes for analysis: identity and government expectations.

Participants

To understand the consequences of a policy for the broad range of people for whom it was intended, I required local knowledge of the everyday experience and the expert understandings of practical experience with Title V. There is a difficulty and limitation in sampling urban Indians because the population that actively seeks care or is connected to its community is never comprehensive of the total or estimated census population. For this original research, I overcame this limitation by focusing on administrators of urban Indian health. Purposeful sampling selects participants for a specific reason as it attempts to guarantee that the voice of participants are reflected for greater understanding (Creswell, 2009). I used purposeful sampling to guarantee the voice of participants would be reflected for a greater understanding (Creswell, 2009) of Title V. This key informant approach allowed me to explore the meaning of Title V in-depth from individuals recognized for their central role in Title V efforts.

In-depth interviews were conducted with a sample of 15 executive directors or program managers at UIHOs across the United States, while 2 interviews were conducted with executive leadership from agencies that provide administrative support or oversight of urban Indian health care programs. The number of participants' represented all types of existing UIHO programs (levels of care), the geographic diversity of the UIHP, and allowed for the inclusion of stakeholders identified working outside a characteristic UIHO site (Table 4.2).

Interviews

Though interviews have their limitations, my familiarity with my participants and the work they do provided a solid base from which I built interest for participation, and

my level of understanding of Title V, from extensive review of Title V legislation, allowed me to ask questions for which I had no preconceived answers. In-depth personal interviews were conducted by telephone with 17 participants. An interview guide was created to conduct these semistructured interviews. The length of interviews varied between 45 to 120 minutes and the raw data were reviewed by me before transcription by a professional transcription service. The interview responses were transcribed in the form of narratives, in keeping with the nature of the participant's answers. I asked questions relating to the purpose or organization of their agency, their role held within that agency, and various questions about their experience with Title V. From their responses, I have selected two themes that represented issues of social justice or self-determination: 1) identity of self and organization, and 2) government expectations of their UIHO.

Data Analysis

Because qualitative research involves the researcher as an instrument (Creswell, 2009), I engaged in conversational, in-depth interviews with key stakeholders. During or immediately after my interviews, I noted observations and general to specific impressions about the interview in a journal. This led to data reduction to organize and prepare the raw data, which included transcription of audiotapes (done by a professional transcription service), typing field/journal notes, and sorting the data by type (interview) or source (field notes). This step provided a general sense of the overall context and allowed me to check the transcripts for mistakes.

I then read and reread the transcribed data to become familiar with the data and to record my overall impressions and ideas about the interviews. During this analysis of the transcriptions, I conducted a line-by-line coding of the data to look for and interpret

emerging themes. Coding line-by-line was used to start creating topics by identifying descriptive words. All emerging themes were coded in a different color and categorized. Each theme was studied intensively, to see if any multiple themes can be merged or separated (Creswell, 2009). I knew I reached saturation of the data when I had sufficient depth of information and redundancy of data that met the purpose of the study. For this study, I am focusing on two themes-- identity and government expectations, which emerged during analysis that best answer the research question, how are UIHOs understood in federal health care policies?

Themes

Identity

From the interviews, two distinct issues of identity emerged: 1) definition of urban Indian; and 2) identification as an UIHO. Stakeholders who identified as American Indian told me whether they considered themselves "urban" and what that definition meant. An extension of the definitions given for urban came the definition of an UIHO, or more correctly, how UIHOs perceive they are defined by others.

Urban Indian Definition

Participant 4 (male): "I use the term urban Indian pretty much for lack of a better term."

Participant 5 (male): "So I'm not a fan of the term urban Indian. I try to, whenever I can, to stay away from it. In my opinion, it's really a decisive, you know, invention that really comes down to if you're tribal or if you're urban Indian. And that's not true. I mean, we're just American Indian people who at the time happen to be living in urban centers. Right now I live in (this city). And a year from now I could be back on the rez. I have no idea how--just because I don't live on the reservation doesn't all of the sudden mean that my status has changed."

Participant 14 (female): "I think it's (using the term urban Indian) controversial. I did not grow up on my reservation, but I went out there every summer. I participate in tribal events and tribal activities. However, I define myself as an Indian who lives in an urban

area, not necessarily an urban Indian…it's no fault of my own that we came to the city. I mean, I'm your cousin who relocated. It won't be forever. I'm also going to do my best to represent."

Participant 12 (female): "I was born and raised on the reservation and of course lived probably about the same amount of time now off the reservation. I think because I've grown up on the reservation I don't really identify as either, but I'm sensitive to the needs of both. You know, I don't really make the differentiation. I know that there's a lot of people that do…I understand the considerations for tribal government in terms of needing to protect tribal sovereignty… but at the same time having lived in the urban environment for as long as I have, I also see that there are not so much differences in our disparities."

Participant 11 (female): "This is a hard one to answer because sometimes I do and sometimes I don't (define self as an urban Indian). I mean, I don't ever deny it. That's why it sounds kind of bad because when I am in places where there's an American Indian who has been taught by their parents, grandparents, and great-grandparents to always introduce themselves by lineage…when I hear something like that I think they do that in every single instance because that's what they've been taught. But me, I probably wouldn't do that unless someone asked because it's too distant."

UIHO Identity Issue

Two types of meaning emerged from the theme of identity for an UIHO: identification as established by the Title V policy and identification perceived by others outside the UIHO. Differences arose between views of urban Indians as self-determined and the idea of self-determination existing only with tribes or tribal land. The delivery model of care for the Indian Health Service is sometimes referred to as the ITU--- IHS, Tribal, and Urban, and the IHS budget is allocated principally to the I and the T. This concept became a theme in many interviews as the reason UIHOs are understood differently by clients or from the IHS system of care.

Participant 8 (male): "You know, Title V was crafted within the IHCIA because I think there was a pretty good awareness throughout Congress and at least in the Indian Affairs committees, and in the agencies serving Indians they had this large outflow of Indians, and this resulted in an urban Indian setting then. Before this, the argument of the government was Indians have been citizens since 1924, so you are eligible for whatever other help, like social welfare programs, are available in the urban areas. As a policy

statement, that's a glowing comment but the realities turn out to be a lot different…our treatment of the urban Indians has been less than glowing, I might add."

Participant 13 (female): "I honestly think that urban Indians do have self-determination as an extension of their tribal rites, I really do. I think that the obligation of the federal government doesn't end based on location of a Native American, especially when it comes to health and education"

Participant 6 (male): "Urbans definitely identify as a collective and as a community."

Participant 4 (male): "Well, from an urban perspective, I think it (our self-determination) is attached to sovereignty. I think things like Medicaid policy as it relates to say our state's Medicaid program provides us self-determination. That it does affect Indians not just on a reservation but in the city, and it should be a consultation policy requires so that they understand that you can't just deal with a tribe in a predefined geographic area of the reservation. These policies also affect urban Indians."

Participant 16 (female): "We don't have the same standing as a sovereign nation or leader to make demands of the government. The voice of urban Indians doesn't lie with the individual communities or the individual person. It lies with the leadership within their own tribes."

Participant 5 (male): "The Lakota tribe in South Dakota can't be responsible for the health and well-being of Lakota people living in L.A., or for the Lakota people living in Seattle, or Chicago, or New York and Miami, and everywhere else. It can't happen. We don't have the infrastructure. The easiest remedy is for the urban communities in those areas take up that responsibility. But the fact of the matter is that urban communities don't have the government-to- government status, don't have treaties, don't have the right to self-determination, and aren't sovereign nations. They're just communities."

Participant 8 (male): "I would like to say that self-determination can be applied to urban Indians but I don't believe it is. American Indians are members of tribal nations, but we aren't sovereign citizens. The right to self-determination extends to tribes as sovereign entities, not to individuals."

Participant 4 (male): "Yeah, we're a subclass. We're the stepchild of a subclass. The Indian money that's available goes to others. Within Indian health, we're like the stepchild so we get less than 1% of the funds for 60% of the population. It's like people don't want to get outdone by our story. The Indian Health programs, the IHS and tribes don't want urban Indians' story to be heard, to overwhelm their victim story. And I don't mean to say that they're a victim, that's not what I'm saying. What I'm saying is they feel shortchanged by the federal government and the government's obligation to them. They don't want to hear about urbans' problems until theirs are solved."

Participant 5 (male): "There's certain distinctions between the T and the U in the I/T/U system, but the huge distinction is between the I and the T and the U. The I is the

government run health care system. And the T and the U are contracted out either to the tribes or our urban nonprofits. And what we see there is that as with anything the federal government does, it's not always the most efficient, or you know, highest quality provider of services. That's true for more than just health care… so on the tribal and urban side, we are a business just like any other business."

Government Expectations

Due to the political nature or political existence of an UIHO, every participant in this study spoke about their relationship to the federal government, and the responses or clarification they must often provide to protect their Title V status and funding. In this line of questioning, the theme of diminishing federal trust obligation for the provision of care to urban Indian populations emerged.

Participant 2 (male): "I'm seeing a trend towards restricting Indian monies to members of federally recognized tribes only. This is contrary to the nature of Indian policy, to the intent of the IHCIA. With passage of the IHCIA in the Affordable Care Act, the feds are dangerously close to ignoring the Indian population served by UIHOs….they (the federal government) need to understand the trust obligation extends to all Indians throughout the U.S. That was the point of Title V."

Participant 11 (female): "I witnessed (U.S. Senators) trying to define Indians, they were talking about how they could figure it out or decide. And to me it's like, why does the U.S. government think they can decide instead of how the tribes define an Indian?"

Participant 14 (female): "I mean, there are a lot of things that are left to be desired as far as the levels of Title V funding and acknowledgement of the Indian people. People at the federal level, at the state level, are not required to know or understand or acknowledge the rules and the laws that are in place regarding Indian People. For instance, we spend a lot of time educating our legislators and then by the time they're educated, and we find friends in the state or federal level, their term is up and then we start the process all over. The laws are only as strong as the folks who acknowledge them."

Participant 4 (male): "There's a political nature to the work we do. There has to be because you see how fledgling we really are when the administration (federal) can zero you out. Then you really know who your friends are, like the tribes and the tribal leaders, NIHB, and everybody else that was pushing to put us back in. So it's important to understand that these policies that are made in Washington really directly affect our ability to provide healthcare."

Participant 5 (male): "I believe that there will always be attempts by the federal government to diminish its trust responsibility out of a sense of fiduciary concerns. Serious, serious cuts have been proposed in the past couple of months… (cuts to health) that are just incomprehensible."

UIHOs are funded through Title V contracts (appropriations by Congress fund these contracts) that are administered through the urban Indian Health Program of the Indian Health Service. When participants were asked about their relationship with IHS, almost all spoke about the inability of the IHS to speak on behalf of the urban Indian health agencies. Others spoke about the elimination threat in 2006 by George W. Bush and how a lack of protection from the federal government for UIHOs (and extension of the federal trust obligation for the provision of health care to all Indians) led programs to infrastructure changes.

Participant 7 (male): "You know our area office includes us in all the consultations and all the advisory committees. In fact, they wanted us to start participating as members of budget advisory committees, but the IHS told them no. They said that's strictly reserved for sovereign leaders. Then you have other area offices that are just anti-urban like someplace like North Dakota, I don't know what are they are, but they just want to take that urban money and put it in the IHS pocket for their clinics."

Participant 4 (male): "Other than NCUIH, I don't believe anyone else speaks on behalf of urban health issues at the federal level. I think just in general as part of overall IHS funding, I think NIHB does, but I think IHS' tribal interests far exceed the urban interests."

Participant 11 (female): "In my opinion, I'm not saying that IHS isn't helpful, they just can't advocate for urbans. They're the government. I mean, they can be totally opposed to the President, just like Chuck Grim was (former Director of IHS during George W. Bush administration). But they can't do anything about it. I mean they could quit and then do something about it, but IHS is the government."

Participant 13 (female): "I think (IHS) they're thinking when they give us money that we should be leveraging and bringing in other dollars also. I'm seeing more of them saying you need to be going after FQHC status and you need to be going after community health dollars."

Participant 17 (female): "I found it interesting that after Bush proposed elimination (of Title V funding) that out urban Indian program office said 'we can't help you if you're shut down, but the thing we will help you with is applying for 330 funding.' That's when

we knew our UIHO was in jeopardy and no one in the IHS system was going to bat for us. So we've lowered our reliance on Title V funding. I don't think we had a choice to keep operating and to serve our urban Indian population."

The essence of these quotes reflects the ways UIHO stakeholders continuously define who they are as Native people, and their identities bring an intrinsic understanding of the population they serve. The political nature of what it means to be Indian, and the ways in which urban Indians are identified by other Indians or by the federal government, impacts how UIHOs conduct business. They recognize that they must be the voice that reminds the community of their rights to receive health care, regardless of where they live or how they came to the urban area.

Conclusions

Health status does not appear to be determined just by the availability of health services or prescription drugs; it is the result of layers of factors, such as socioeconomic status, education, spiritual wellness, cultural and family support systems, employment opportunities, tribal status, etc. (refer to Figure 4.1). To this end, UIHOs have begun to weave a network of support systems and partnerships among federal, tribal, and private foundations in order to address all these factors, which contribute to the health and well-being of urban Indians seeking health care; it is also the foundation of the identity created among UIHOs. At the intersection of federal Indian policies that created the trust responsibility to provide health care and urban relocation under the guise of providing more services and opportunities is a space that urban Indians define for themselves. It was important for the participants in this study to create health care programs and services that were culturally relevant, and honor a connection to the history, culture, and respect for all American Indians. While the concept of self-determination for urban

Indians is problematic, what is critical to an UIHO is its connection to its "Indianess" rather than to tribal identity. These stakeholders all considered health care for urban Indians an entitlement, but this entitlement really came down to the federal funding to provide the trust obligation for urban Indians.

An interesting point of topic raised by the participants was the suggestion or push made by federal personnel from the Urban Indian Health Program, Indian Health Service, and the Health Resources and Services Administration (HRSA) for UIHOs to establish status as a federally qualified health center (FQHC), thereby making them eligible for additional federal health care funding. The origins of Title V were built on community and public health ideals that used local solutions to address local health issues (Bergman, Grossman, Erdrich, Todd, & Forquera, 1999). Some UIHOs began as community health centers or FQHCs prior to enactment of the IHCIA; they have created a unique model of primary medical, behavioral, and dental health care utilizing their 330 dollars and leveraging Title V status and funding to provide AI/AN specific care. In fact, many UIHOs look to other funding to enable their agencies to continue and grow beyond their Title V beginnings, thereby allowing flexibility of these UIHO to provide access at no or low cost to all AI/AN regardless of federal recognition status. Because these combined UIHO/FQHCs are considered successful, self-sustaining organizations, many stakeholders spoke about the trust in their model of care over Title V funded only UIHOs. Because of the threat of program elimination by George W. Bush in 2006, some agencies made concerted efforts to move away from Title V funding and strengthen their sustainability by applying for community health or FQHC status.

Social Justice Issue

I would argue that no research should be conducted with Indigenous Peoples that is not in some way directed by a community and aimed toward improving the life chances and situations of specific communities and American Indians writ large….TribalCrit endeavors to expose the inconsistencies in structural systems and institutions….[Brayboy, 2005, pp. 440-441]

The voice of UIHOs are excluded from the Indian Health Service budget consultation process, and it appears that the voices of the nearly 70% AI/AN who live in urban areas are not part of policy creation; tribal governments can speak on behalf of their tribal members through federally recognized tribal sovereignty or self-determination. Though UIHOs continued to be funded at 1% of the IHS budget, and operate in the urban areas where the majority (nearly 70%) of all self-identified AI/AN reside, how is this socially just? The voice of urban Indians for their health care is excluded as equal. And yet, federal agencies promote and encourage the UIHOs to seek other federal opportunities in order to meet the need of urban Indians; oftentimes, they are told "you will never receive the same level of funding as the tribes do." The health inequities experienced by urban Indians have yet to be adequately addressed by policy, and it is within the realm of policy that the federal government created its responses to its trust obligation.

Governments that evolved from the colonization of their countries have created health organizations with Indigenous or Aboriginal offices to initiate, advocate, or liaison the health issues of their Indigenous populations. A fundamental question that frames the federal relationship between the U.S. and American Indians is whether the tribe or individual member are self-determined, autonomous, and federally recognized political entities. Why the federal government would want to separate its federal trust obligation

from American Indians living off-reservation is a strong political action deeply rooted in postcolonial federal policies of assimilation. During a book signing to promote his latest work in 2010, attorney Walter Echo-Hawk Jr. stated it was time for Indian policy to *soften the harsh edge of manifest destiny and reform the dark side of federal Indian law once for all,* and one goal towards this would be strengthening the law so it *comports with the United Nations minimum standards* (Attocknie, 2010).

TribalCrit acknowledges that American Indians are more than a racial classification and though their lived experience has a connection to colonization, their narratives must be explored to understand the connection to who they are now and move away from a romanticized, dominant, or outsider view of who Indians are. UIHO stakeholders are seeing continued attempts by the federal government to limit or even end the trust obligation to urban Indians. Analysis of this phenomenon through the lens of TribalCrit acknowledges that colonization is endemic to society; the histories of federal Indian policies are a colonized response to force assimilation of the Indigenous peoples of the U.S., and it appears that elements of assimilation are still endemic to policy and appropriations for urban American Indians. Social justice in non-ideal contexts are characterized by dependence, vulnerability, and a potential for the interests and aspirations of a minority population to be limited and thwarted by the collective impact of the various elements of the larger social structure (Powers & Faden, 2006). This is seen in the history of federal Indian health policy. UIHOs who still see unjust representation for urban Indians have created a unique model to build sustainability and weather Congressional and Executive whims. Success has come to these stakeholders who have not forgotten where they come from and what they have been through.

Recommendations to address the federal trust obligation for urban Indians, thereby including the unique UIHO system and voice for urban Indian health needs, would be:

1) Challenge government assertions that could restrict its federal obligation/trust responsibility to ONLY federally-recognized tribes and therefore tribal citizens/members.
2) Funding at levels necessary to meet health care costs and delivery of care. IHS still spends less federal dollars on health care per capita than any other federal health budget.
3) Increase specific data and policies to address Indigenous peoples' issues, as listed in the UNs 2010 State of the World's Indigenous Peoples report. Due to the overall low percentage of American Indians in the U.S. population (and lack of funding to conduct large-scale American Indian-specific research), Indian data samples are rare and often Native peoples are combined with other minority populations for the purpose of statistical significance. Health data that specifically identify and sample from urban Indian populations could have a significant impact on the system of care for urban Indians because accurate data could inform policy and funding distribution.
4) Use of community-based participatory research as a capacity-building approach for policy advocacy to eliminate health inequalities (Israel et al., 2010). The inclusion of the urban Indian voice about their SDOH could influence policymakers' willingness to address social, cultural, and economic policies as health policy.

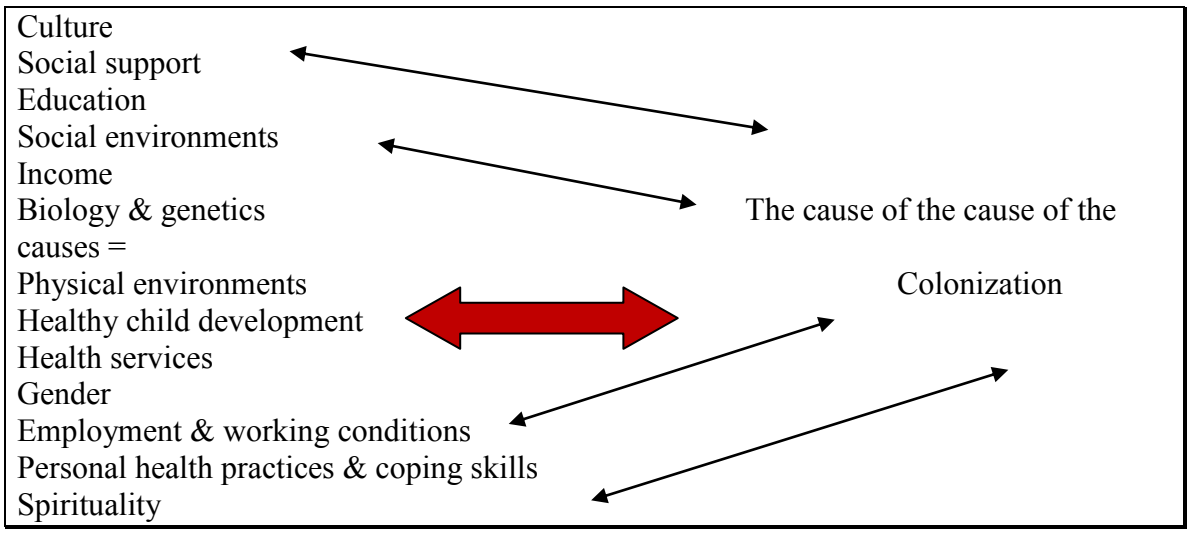

Figure 4.1: SDOH of Indigenous Peoples

Table 4.1: Tribal Critical Race Theory (Source: Brayboy, 2005)

Tenet #	TribalCrit
1	Colonization is endemic to society.
2	U.S. policies toward indigenous peoples are rooted in imperialism, white supremacy, and a desire for material gain.
3	Indigenous peoples occupy a liminal space that accounts for both the political and racialized natures of our identities.
4	Indigenous peoples have a desire to obtain and forge tribal sovereignty, tribal autonomy, self-determination, and self-identification.
5	The concepts of culture, knowledge, and power take on new meaning when examined through an indigenous lens.
6	Governmental policies and educational policies toward indigenous peoples are intimately linked around the problematic goal of assimilation.
7	Tribal philosophies, beliefs, customs, traditions, and visions for the future are central to understanding the lived realities of indigenous peoples, but they also illustrate the differences and adaptability among individuals and groups.
8	Stories are not separate from theory; they make up theory and are, therefore, real and legitimate sources of data and ways of being.
9	Theory and practice are connected in deep and explicit ways such that scholars must work towards social change.

Table 4.2: Characteristics of Study Participants

Participant	**Gender**	**Identity** +	**Years in position** ++	**Geographic Location** *
1	M	AI	>10	Billings
2	M	AI	>30	Portland
3	M	AI	>30	California
4	M	AI	>10	Phoenix
5	M	AI	>10	Nashville
6	M	AI	>10	California
7	M	AI	>30	Phoenix
8	M	AI	>40	Nashville
9	F	N-AI	>10	Nashville
10	F	N-AI	>20	Aberdeen
11	F	AI	>10	Oklahoma City
12	F	AI	<10	Bemidji
13	F	AI	<10	Portland
14	F	AI	<10	California
15	F	AI	>10	California
16	F	AI	> 10	California
17	F	AI	> 10	Nashville

+ AI= American Indian; N-AI= non-American Indian/Other
++ Approximation of years in agency OR years working w/ urban Indian organizations; to protect confidentiality I have selected years in 10-year increments vs. actual years
***** Based on 12 IHS service areas

References

Attocknie, D. (2010). Echo-Hawk explains manifest injustice in new book. Native American Times Sept 27, 2010. Retrieved on 9/28/2010 from http://nativetimes.com/index. php?option=com_content&view=article &id=4299:echo-hawk-explains-manifest-injustice-in-new-book&catid=49&Itemid=25

Bergman, A.B., Grossman, D.C., Erdrich, A.M., Todd, J.G., & Forquera, R. (1999). A political history of the Indian health service. *The Milbank Quarter, 77*(4), 571-604.

Braveman, P.A., Egerter, S.A., & Mockenhaupt, R.E. (2011). Broadening the focus: The need to address the social determinants of health. *American Journal of Preventive Medicine, 40*(1S1), S4-S18.

Chinitz, J., & Christian, D. (Eds.). (2009). An *American debt unpaid: Stories of native health*. Health Rights Organizing Project. Northwest Federation of Community Organizations.

Commission on Social Determinants of Health. (2008). Closing the gap in a generation: Health equity through action on the social determinants of health. Final report/executive Summary. World Health Organization.

Creswell, J.W. (2009). *Research design: A qualitative, quantitative, and mixed method approaches* (3rd ed.). Thousand Oaks, CA: Sage.

Darder, A., & Torres, R. (2004). *After race: Racism after multiculturalism*. New York: New York University Press.

Denzin, N.K., & Lincoln, Y.S. (eds.). (2005). Sage handbook of qualitative research (3rd Ed.). Thousand Oaks: SAGE.

Denzin, N.K., Lincoln, Y.S., & Smith, L.T. (Eds.) (2008). *Handbook of critical and indigenous methodologies*. Thousand Oaks, CA: Sage.

Gracey, M., King, M. (2009). Indigenous health part 1: Determinants and disease patterns. *The Lancet, 374*, 65-75.

IFAD (The International Fund for Agricultural Development). Statistics and key facts about Indigenous peoples. Retrieved May 18, 2011, from http://www.ruralpovertyportal.org/ web/ guest/topic/statistics/tags/ indigenous%20peoples

Indian Health Care Improvement Act of 1976, Pub. L. No. 94-437, § 501 et seq. 90 Stat. 1400 (1976).

Israel, B.A., Coombe, C.M., Cheezum, R.R., Schulz, A.J., McGranaghan, R.J., Lichtenstein, R., Reyes, A.G., Clemement, J., & Burris, A. (2010). Community-based participatory research: A capacity-building approach for policy advocacy aimed at eliminating health disparities. *American Journal of Public Health, 100* (11), 2094-2102.

Marmot, M. (2000). Multilevel approaches to understanding social determinants. In L.F. Berkman & I. Kawachi (Eds.), *Social epidemiology* (pp. 349-367). New York: Oxford University Press.

Marmot, M. (2005). Social determinants of health inequalities. *Lancet, 365*, 1099-1104.

Marmot, M., & Wilkinson, R.G. (2000). *Social determinants of health*. Oxford: Oxford University Press.

Marshall, C., & Rossman, G. B. (2006). *Designing qualitative research* (4th ed.). Thousand Oaks: Sage.

Powers, M., & Faden, R. (2006). *Social justice: The moral foundations of public health and health policy*. New York: Oxford University Press.

Raphael, D. (2006). Social determinants of health: Present status, unanswered questions, and future directions. *International Journal of Health Services, 36*(4), 651-677.

Richardson, V. (2010). Obama adopts U.N. manifesto on rights of indigenous peoples. Washington Times Thursday Dec 16, 2010. Retrieved May 18, 2011, from http://www.washingtontimes.com/news/2010/dec/16/obama-adopts-un-manifesto-on-rights-of-indigenous-/?page=all

Smith, L.T. (2006). The role of research in indigenous struggles for social justice. In N.K. Denzin & M. D. Giardina (Eds.), *Qualitative inquiry and the conservative challenge (*pp. 151-174*)*. Walnut Creek, CA: Left Coast Press.

Stephens, C., Porter, J., Nettleton, C., & Willis, R. (2007). UN declaration on the rights of Indigenous peoples. *The Lancet, 370* (9601), 1756, doi:10.1016/S0140-6736(07)61742-5

The Harvard Project on American Indian Economic Development. (2008). *The state of the native nations: Considerations under U.S. policies of self-determination.* New York: Oxford Press: Author.

U.S. Commission on Civil Rights (2003). *A quiet crisis: Federal funding and unmet needs in Indian country.* Washington, DC.

U.S. Commission on Civil Rights (2004). *Broken promises: Evaluating the Native American health care system.* Washington, DC.

Urban Indian Health Commission (2007*). Invisible tribes: Urban Indians and their health in a changing world.* Seattle: Urban Indian Health Commission.

Urban Indian Health Institute (2004). *The health status of urban American Indians and Alaska Natives: An analysis of select vital records and census data sources.* Seattle, WA.

Urban Indian Health Institute (2008). *Reported health and health-influencing behaviors among urban American Indians and Alaska Natives: An analysis of data collected by the behavioral risk factor surveillance system*. Seattle, WA.

United Nations. (2009) State of the world's indigenous peoples. Retrieved on 22 May, 2011, at http://www.un.org/esa/socdev/unpfii/documents/SOWIP_web.pdf

United Nations Permanent Forum on Indigenous Issues. (2012). *Historical Overview*. Retrieved March 25, 2012, from http://social.un.org/index/IndigenousPeoples/Declarationonthe RightsofIndigenousPeoples/HistoricalOverview.aspx

Warne, D. (2009). Ten Indian health policy challenges for the new administration in 2009. *Wicazo Sa Review, 24*(1), 7-23.

Zuckerman, S., Haley, J., Roubideaux, Y., Lillie-Blanton, M. (2004). Health service access, use, and insurance coverage among American Indians/Alaska natives and whites: What role does the Indian health service play? *American Journal of Public Health, 94*(1), 53-59.

CHAPTER 5

CONCLUSION

Dissertation Summary

The purpose of this study was to explore the current state of Title V of the Indian Health Care Improvement Act from the perspective of Urban Indian Health Organization stakeholders, namely the people holding positions of administrative leadership: executive directors, chief executive officers, and program managers. Employing a constructivist approach for the study, and using interpretive policy analysis, I set out to understand these stakeholders' communities of meaning about Title V. Through interviews with 17 participants, extensive document analysis, and observation, I collected national data over the course of 3 years. During this time, the Indian Health Care Improvement Act, and consequently, Title V were given permanent authorization via the passage of the Affordable Care Act. In fulfillment of the dissertation requirement, I selected the Multiple Article Path option, so Chapters 2, 3, and 4 correspond to articles 1, 2, and 3, consecutively. In this chapter, I will provide the summary and major conclusions for each of my three journal articles, followed by the overall discussion about the implications of this study.

Chapter 2: Urban American Indian Health in the 21st Century

This article provided an overview of the U.S. government's eras of Indian policy and subsequent health policies that the urban American Indian populations have been

subjected. I presented the history of the creation of urban Indian communities due to the result of federal termination and relocation policies of the 1950s and 1960s, as well as description of the growing health inequities experienced by urban Indians. The concept of the federal trust relationship extending to all American Indians regardless of their location on or near a reservation is the basis for the obligation to include urban Indian language in Title V of the Indian Health Care Improvement Act (IHCIA). The entitlement of federal health care provisions to American Indians, as defined in the IHCIA, was given permanent authorization with the passage of the Patient Protection and Affordable Care Act, also known as the ACA, in March 2010. Due to federal policy, urban Indians found themselves cut off from support and services provided to reservation and tribal-based communities that ultimately caused urban Indians to 1) experience greater health inequalities compared to general society and 2) create a unique model of care and support for urban Indians. This article suggests that the federal obligation to provide health care to urban Indians must be protected in light of the possible repeal of the ACA. Congress must understand that urban American Indians are not just another minority group, but a legacy of the assimilation policies of the U.S. government that are still reflected in the lack of adequate funding to provide for urban Indian health care and in the on-going health inequalities experienced by the urban Indian population; forgetting that the purpose of the IHCIA was to raise the health status of all American Indians and Alaska Natives to the parity of the general society, and that Title V was to make health services more accessible to urban Indian communities. This article will be submitted for publication in the *American Journal of Public Health*, the peer-reviewed journal for the American Public Health Association, a U.S. professional public health society.

Chapter 3: Communities of Meaning: Interpreting the Impact of Title V on Urban Indian Health

The purpose of this descriptive-exploratory study developed from a lack of understanding by the general public about the UIHO delivery system and greater lack of research found in the literature about the UIHO experience. For this article, I presented Title V communities of meaning as defined by the experience of 15 executive leaders in Urban Indian Health Organizations (UIHOs). Whereas a traditional policy analysis may look at whether a policy is fulfilling its intended purpose, this study sought to understand the impact, or lived experience, of the stakeholders who implement the policy. Utilizing interpretative policy analysis (IPA) as a framework to understand the meaning of Title V by this population, I conducted document analysis, observation, and conversational interviews. I wanted to know the shared interpretation (meanings) of Title V by the people (communities) who oversee the provision of care established by the policy. The three major questions I addressed during these 15 conversational, in-depth interviews were: 1) what is the role of Title V, 2) how did the participant learn about Title V, and 3) how did the participant define Title V.

While all participants' shared similar definitions and historic context of Title V, these meanings were often taught or passed on by other UIHO executive leadership -- particularly two seasoned UIHO directors, Martin Waukazoo and Ralph Forquera. This information is of special concern since the trust responsibility (and distribution of the Title V contracts and grant monies) for provision of care to urban Indians is managed by the office of Urban Indian Health Programs (UIHP) of the Indian Health Service (IHS). The relationship between UIHOs and IHS appears to be cold, whereby UIHOs take

accountability and responsibility for their work in accordance with their agency or community standards; these are often based on the health care needs unmet by Title V monies. Also, UIHOs take responsibility for their own advocacy for urban Indian health as well as finding other funding opportunities to meet community needs, because they felt no other Indian health agency, organization, or tribe, can or will speak on behalf of the urban Indian population. The irony of this stems from the failure to recognize the trust obligation to provide health care to all American Indians extends to a population that, according to the 2010 U.S. Census data, 70% of the entire American Indian and Alaska Native population live in urban areas. Yet funding allocated by IHS to the UIHP constitutes 1% of the overall IHS budget. This article will be submitted for publication in *AlterNative: An International Journal of Indigenous Peoples*, a global, multidisciplinary peer-reviewed journal.

Chapter 4: Are Federal Health Policies for Urban American Indians Socially Just?

This article investigated how the voice of UIHOs is included in the federal health care policies, and how inclusion --or exclusion, is a symbol of social justice. In-depth, conversational interviews were conducted with 17 UIHO stakeholders across the U.S. for this descriptive-exploratory study. My experience as a former UIHO executive director, paired with my identity as both a citizen of the Chickasaw Nation of Oklahoma and as an urban Indian, was essential in understanding the perspective of my participants because they have created culturally specific spaces/agencies to provide urban Indian health care; I believe this same perspective is critical when creating socially just health policies for urban Indians. I drew upon the theoretical framework of Tribal Critical Race Theory

(Brayboy, 2005) to understand the emerging themes from the interviews as they related to federal Indian history, identity, health inequalities, and in hearing the voice of stakeholders. These elements contribute to a social justice perspective of Indian health because they explicitly connect the justice issues of access, funding, and provision of services to a historically marginalized population.

The two themes on which I focused my analysis were identity and government expectations. The primary finding of this study shows UIHOs have weaved a network of support systems and partnerships among themselves and with federal, tribal, and private organizations that has created a unique politicized and cultural identity, one which has not been defined by federal legislation. The act of self-identification is an act of self-determination. The fundamental question about the federal trust relationship between the U.S. government and American Indians is whether the tribe or individual tribal member are self-determined, autonomous, and federally recognized political entities. Events like the Reagan and Bush II Administrations' elimination of funding to the UIHOs, thereby separating the U.S. federal trust obligation from American Indians living off-reservation, are perceived as a strong political action deeply rooted in the federal policies of assimilation. This article will be submitted for publication in the *Journal of Indigenous Social Development*, a peer-reviewed journal whose purpose is to advance research and policy making relevant to Indigenous peoples' social and economic well-being.

Interconnectedness of the Three Chapters

These three articles were the result of, or driven by, my original research interest to understand the meaning of Title V of the Indian Health Care Improvement Act as it approached its 36th year of enactment. This study approached an understanding using

Yanow's IPA model (2000) to identify what Title V means to the stakeholders and not approaching this study as a traditional policy analysis from the perspective of the policy makers. The three steps of the IPA-- document analysis, observation, and interviews, were followed to collect the data necessary in understanding the historic, cultural, and contextual meaning of Title V by stakeholders in the delivery of health care to urban American Indians.

Conclusion of Overall Research

This dissertation is nearly complete at the same time the U.S. Supreme Court is hearing arguments on the constitutionality of the ACA. If the ACA is found unconstitutional, then the Supreme Court will rule to disallow all or perhaps sections of the law they deem unlawful. As you are now aware, embedded within the ACA is Title X, otherwise known as the Indian Health Care Improvement Act. The permanent authorization of the IHCIA contained by the ACA has given urban Indians a newfound permanent recognition in IHS. This study supports what many others have stated; that the Indian health care system (IHS, Tribal, and Urban Indian Health Programs) is woefully underfunded, and that the health inequalities experienced at the time of the IHCIA passage are still prevalent. The promise of health care for urban Indians, through Title V and the extension of the federal trust obligation, may be secured through enactment of the ACA.

What does this mean for social work? As I stated in Chapter 1, I understand as a social worker that policy is often developed in response to social problems, and that the policy can dictate how we do the work to address those social problems. I believe social problems experienced by historically marginalized populations like American Indians are

the result of the U.S. historical values and ideologies, economic and political structures, and institutionalized discrimination and assimilation. Professionally, we challenge forms of social injustice and inequality experienced by vulnerable and oppressed peoples, such as issues of poverty and discrimination.

As an Indigenous woman, I am concerned with the health inequalities disproportionately experienced in urban Indian communities; as an indigenous social work researcher, I am exploring the layers of social, political, and racial determinants that have contributed to the health conditions of a historically marginalized population. In so doing, I am contributing to the understanding of a unique racialized *and* politicized minority population--urban American Indians--who continue to disproportionately experience health inequalities nearly 36 years after the creation of a federal response to reduce the inequalities.

Implications

This study fills a gap in the research literature about the experience of Title V Urban Indian Health Organizations and may lend to the development of more strategic social work responses.

Social Work Policy

The voice of UIHOs at the federal level is still provided through the Indian Health Service because urban Indians do not hold the same rights of self-determination in policy-making decisions. Findings and interpretations of this study have the potential in guiding social work advocacy towards socially just policies for the urban Indian population. As stated in the 2008 Urban Indian Health Institute report, "…there is no national, uniform policy regarding urban Indian health" (p. 1). With the permanency of

Title V, UIHOs enter a new political arena at the federal level for budget and policy consultation on behalf of the urban Indian populations served. For the thousands of urban Indians who do not receive care from an UIHO, or who are not spoken for by a tribal government, social workers could raise the issue of federal trust and accountability, as well as awareness of the need for increased federal funding to accomplish the intent of Title V and/or the federal trust obligation period.

Social Work Research

This study is the first of its kind filling an enormous void in the research literature. A better understanding of the model of care created and provided through UIHO is needed; it was determined in this study that UIHOs have begun looking at, and what they perceive as, viable, sustainable, and successful agencies that reflect the changing landscape of health care delivery. There is potential for researchers to address reasons for insufficient data on urban Indian populations. Other theoretical models or frameworks may by adapted to understand the issues faced by urban Indians; just as there is no one policy that addresses urban Indian health, nor is there just one way to interpret the experience of urban Indians.

Strengths and Limitations of the Study

This study has much strength because I utilized a constructivist approach to establish meaning and understanding of the provision of urban Indian health care, established by the passage of the IHCIA and Title V. This approach valued the experience and the voice of my participants, and is just beginning to tell the story of the UIHO role in reducing health inequities of the urban Indian population. Therein rests the

limitations of this study because only 17 participants were able or willing to contribute to this study. Further study is warranted.

Future Research

Article 3 raised a question for further study about the shared social determinants of health among Indigenous and Aboriginal peoples worldwide. I want to address the global health inequalities experienced in countries that were founded on colonization and had similar assimilation policies as the U.S., like Canada, New Zealand, and Australia. I would like to use a community-based framework to look beyond the federal insufficiency of funds to address the social, cultural, and structural barriers that may be limiting access by American Indians to health care, which may be the contributing factors that contribute to generational continuation of health inequality or disparities.

References

Brayboy, B.M.J. (2005). Toward a tribal critical race theory in education. *The Urban Review, 37*(5), 425-446.

Urban Indian Health Institute (2008). *Reported health and health-influencing behaviors among urban American Indians and Alaska Natives: An analysis of data collected by the behavioral risk factor surveillance system*. Seattle, WA.

Yanow, D. (2000). *Conducting interpretive policy analysis*. (Sage University Papers Series on Qualitative Research Methods, Vol. 47). Thousand Oaks, CA: Sage.